The Unmet Psychosocial Needs of Haematological Cancer Patients and their Impact upon Psychological Wellbeing

Thesis submitted in accordance with the requirements of the University of Chester for the degree of Doctor of Philosophy

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I declare that the material being presented for examination is my own work and has not been submitted for an award of this or another Higher Education Institution.

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Brooke Elizabeth Swash – The unmet psychosocial needs of haematological cancer patients and their impact upon psychological wellbeing.

Unmet psychosocial needs indicate a desire for additional support in cancer patients, having a direct clinical utility in directing the provision of supportive care. There is evidence in wider cancer groups that unmet needs relate to psychological wellbeing but this relationship has yet to be fully explored and factors that may explain or moderate this relationship yet to be examined. There has been little investigation of type or prevalence of unmet need in haematological cancer patients, however, haematological cancers are noteworthy for their high levels of associated distress. Understanding causality of distress is key to the effective implementation of supportive care services.

This thesis aimed to highlight the unmet needs most relevant to haematological cancer patients and to explore their impact upon psychological wellbeing. This thesis comprises four interconnected research studies: a systematic review exploring existing knowledge of unmet needs; a qualitative exploration of patient experiences of unmet needs and their impact; a quantitative questionnaire study of unmet need and psychological wellbeing in newly diagnosed haematological cancer patients, placing a special emphasis on the difference between active treatment and watch and wait regimes; and, a second quantitative questionnaire study that explores unmet need, psychological wellbeing, and psychological flexibility as a potential moderator in their relationship in a sample of haematological cancer survivors.

This thesis demonstrates a relationship between unmet need and psychological wellbeing in haematological cancer patients. Fear of recurrence, concerns about loved ones, being able to do the things you used to, and a need for information were all found to be of relevance. The qualitative study highlighted that patients feel that, as haematology patients, they are distinct from other cancer patients which impacts upon the perceived acceptability of support services and specific barriers to the accessing of support services are presented. Significant correlations between unmet need and key psychological outcomes such as anxiety, depression and quality of life were observed in both quantitative studies. In addition, the concept of psychological flexibility was found to moderate the relationship between unmet need and psychological wellbeing in haematological cancer survivors.

This work has clear implications for both future research and clinical practice. Unmet needs assessment has the potential to be used as a screening tool for overall psychological wellbeing, a way to stratify and understand the specific causes of distress and poor quality of life for this patient group. In the UK, on-going support for cancer patients diminishes at the end of treatment, these findings suggest that further support is needed in order to meet the psychological needs of cancer survivors. Further research is needed to further explore the role of psychological flexibility in cancer-related distress: interventions that target psychological flexibility have the potential to improve both unmet need and distress.

Original Contributions to the Field Arising from Work Undertaken in this Thesis

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Introduction to the thesis

This PhD thesis examines the unmet psychosocial needs of haematological cancer patients, and the psychological impact of living with such a disease. It comprises a series of research studies undertaken in the pursuit of answering this overarching research question: what are the unmet psychosocial needs of haematological cancer patients and how does unmet need relate to psychological wellbeing?

The thesis is presented in such a way as to not only describe the research, but to explain the research process undertaken. As such, the chapters are laid out chronologically in the order the studies were undertaken. Each chapter builds on the last in terms of knowledge gleaned and each informs the development of later studies described in this thesis. Each new study is funnelled down from the last, building and deepening knowledge of unmet psychosocial need as the PhD progresses.

The first phase of this PhD is a systematic review of existing literature examining the unmet psychosocial needs of haematological cancer patients. This review had a dual purpose. It served both as a research study in its own right, collating and evaluating all the existing research relating to unmet need in this patient group and it served the wider purpose of providing the researcher with a thorough appreciation of the strengths and weaknesses of existing research, enabling the researcher to make informed research decisions that were grounded in previous studies.

The major finding of the systematic review was that there was very little published knowledge already in existence. From this baseline, the next stage of this PhD was to undertake a qualitative research study that sought to understand unmet need from the patient perspective. This study aimed to understand the impact and relevance of unmet needs from the lived experiences of patients. In the light of a surprising paucity of existing research, it was felt that an exploration of both type and importance of need was required, along with a deepening of understanding relating to the impact of unmet need on the patient. It was at this point that an exploration of potential differences between haematological and solid tumour patients began to emerge.

Once the qualitative research had established an understanding of importance and relevance of unmet need, the next step was to begin to quantify presence of unmet need and the relationship with psychological wellbeing. This took the form of a questionnaire

study that assessed both unmet need and psychological wellbeing in newly diagnosed haematological cancer patients. A special focus was placed on the differences between patients who were actively treated and those who were monitored via 'watch and wait' post-diagnosis. This tied into the researcher's personal research interests; how do people adjust and cope when diagnosed with a terminal or incurable disease.

At the beginning of the PhD process, it was anticipated that the PhD would consist of just three studies: a systematic review; qualitative exploration of unmet need; and a quantitative assessment of unmet need and wellbeing in newly diagnosed haematological cancer patients. As research progressed, it became apparent that there was another level to which the examination of the relationship between unmet need and psychological wellbeing could be taken and the fourth study presented in this thesis (Chapter 5) was conceived. This fourth study sought to both extend understanding of unmet need in haematological cancer patients by assessing this concept in a survivor cohort and to try and understand the active mechanisms that function within the relationship between unmet need and wellbeing. By adding this study it was possible to expand knowledge beyond what had already been gained through the study of wider cancer groups. It also had the potential to make a novel contribution to how we understand the presence of distress in cancer patients and therefore how we seek to combat distress in this patient group.

The development of this thesis was a journey for a researcher, not just in the deepening understanding of unmet need and how we understand and conceptualise distress in cancer patients, but also in the development of the self as a researcher. At the start of this PhD journey, the researcher was working as a clinician for the NHS, with comparatively little research experience.

The process of undertaking this PhD has:

- Acted as an apprenticeship in applied health research, providing insights into the research process and how it informs clinical practice.
- Shown how research can help clinicians focus time and resources in the right direction.
- Enabled a deeper understanding of the facts and what they mean for patients and for future practice.
- Provided collaborative networks with wider organisations, with the potential in future of making a difference to patients

- Hasn't answered all of the questions asked, but has highlighted areas of future research need.

The chronological structure of this thesis also demonstrates the progression of knowledge and skill development over the three years, detailing the journey of the academic apprenticeship. There is a strong clinical perspective to this thesis, stemming both from the researcher's background which created a desire to improve understanding of clinical need from a practical perspective and a desire for research to have tangible outcomes for patients, but also from the organic way in which the project was conceived. The input of both the nurses and consultants who supported this research must also be acknowledged, as it was their desire to understand that helped to initiate the project and to develop an idea into a project with tangible applications for patient care.

Chapter 1 - An Introduction to Haematological Cancers and the Psychological Wellbeing of Cancer Patients.

Overview

Being diagnosed with a life threatening illness such as cancer can induce significant levels of emotional and psychological distress for both patients and their loved ones (Holland & Alici, 2010; Pitceathly & Maguire, 2003; Carlson et al., 2004). Haematological cancers are a unique and highly diverse groups of diseases that are known to impact upon a person's wellbeing (Molassiotis et al., 2011; Manitta et al., 2011) with key differences between these diseases and solid cancerous tumours, yet there is a lack of published research relating to the specific unmet supportive care needs that are most pertinent to this patient group. Clinical distress is known to be high in haematological cancer patients, at up to 48% (Carlson et al., 2004), a figure that anecdotally is seen as a low estimate. The often intensive nature of treatment for haematological malignancies creates a burden of treatment that can be substantial, impacting upon patients' functional, vocational and social roles (Sherman et al., 2005); and affecting functionality, fertility, sexuality and emotional wellbeing (Paul, 2011). Despite this, psychosocial research into haematological cancers is sparse when compared to that conducted in more common cancer diagnoses. Unmet psychosocial needs, otherwise known as unmet supportive care needs or simply unmet needs, refer to the presence of a desire for help or support in an area that relates to a person's emotional or psychological wellbeing (Boyes et al., 2009; Watson et al., 2012). A poor understanding of the psychosocial issues that are important to a patient group make it difficult to design and implement supportive care interventions that are efficient and effective for patients while also making the best use of limited healthcare resources.

This PhD thesis will identify the unmet psychosocial needs of patients with a diagnosis of haematological cancer. Unmet psychosocial needs are a vital area of research within the field of psycho-oncology as they are able to highlight areas of supportive care that could aid patient coping and reduce distress. Understanding where unmet needs lie can influence both the immediate support given to that patient but also, cumulatively, by observing

trends and population patterns, can influence overall provision of support services within the clinical setting. This thesis will go on to explore the relationship between level of unmet need and overall psychological morbidity in haematological cancer patients, and will attempt to identify any specific factors that may influence the relationship between unmet need and distress. The identification of potential moderators of distress is important when considering the potential implications for both how needs assessment is used within the clinical setting and how interventions that target distress are developed. Understanding mental processes of change enables the promotion of efficient, effective interventions that specifically target the active component for change. In turn this enables interventions to be honed and streamlined while maximising effect, crucial in the current climate of limited resources within healthcare services (Stanton, Leucken, MacKinnon & Thompson, 2012).

This first thesis chapter provides an introduction to the haematological malignancies as a group of diseases and will provide the reader with a background knowledge of unmet need and distress within cancer patients from which subsequent chapters will build. The aims of the thesis will be identified and the methodological approach to the work laid out.

What are haematological cancers and how do they differ from solid tumours?

Haematological cancers are cancers of the blood, bone marrow and lymphatic system (NICE, 2004). There are three overarching diagnoses—leukaemia; lymphoma; and myeloma –within which lie a diverse group of diseases, each with their own specific challenges. Historically, the haematological cancers have been grouped according to the organs that display the most involvement: leukaemias are cancers of the blood; lymphoma of the lymph nodes; and myeloma of the bones. These classifications are still in use; however more modern classifications also make use of the cell populations from which the cancer originates: myeloid cell lines ultimately become cells of the blood system with lymphoid cells ending up as cells within the lymphatic system. Some haematological cancers are extremely acute and require immediate, aggressive treatment while others are so slow growing that they are commonly detected only by chance. Typical symptoms can vary from the lumps which are most typical of lymphoma, to the bone fractures and kidney problems that are characteristic of myeloma, and the fatigue and susceptibility to infection commonly observed in leukaemia. Haematological malignancies are rare in children when compared to the prevalence in adults, although acute leukaemia is the diagnosis given to

one in three children with cancer (CRUK, 2013). As an overall group of diseases, they become more common with increasing age, with people over the age of 65 being the most commonly diagnosed age group. Diagnosis is also more common in males than females (HMRN, 2011). While the haematological cancers may not be the most common cancers found in the UK, in total they are still expected to affect approximately 37 590 people per year (HMRN, 2011).

Leukaemia

Leukaemia is a cancer of the white blood cells that originates from dysfunction in the bone marrow. There are four main types of leukaemia with differences between diagnoses relating to the type of white blood cell affected and whether the disease is chronic or acute in nature. These include: acute lymphoblastic leukaemia (ALL); chronic lymphocytic leukaemia (CLL); acute myeloid leukaemia (AML); and chronic myeloid leukaemia (CML). Leukaemia as an umbrella term, including all sub-types, is the 12th most commonly diagnosed cancer in the UK (CRUK, 2014) and the 9th most common cancer in males. Overall, leukaemia accounts for 2.5% of cancer cases in the UK, yet makes up 2.9% of the total number of deaths by cancer. Survival rates are poorer than for other haematological malignancies, with only 44.3% of patients surviving five or more years.

ALL is a rare cancer, affecting only in the region of 400 people per year in the UK (Macmillan, 2011). It is caused by an overproduction of immature lymphocytes, or blast cells. The overproduction of lymphocytes means that the bone marrow becomes full of these immature cells and is then unable to make new blood cells properly. The lymphocytes are immature and therefore do not fulfil their normal function (to fight infection) to full effect; and due to overcrowding, the bone marrow is unable to make healthy red blood cells and platelets. There are two peaks in the most common age groups diagnosed with ALL; those that are aged 15-25 and those aged over 75. The main treatment type is chemotherapy and approximately 40% of patients diagnosed will be alive at five years post-diagnosis (CRUK, 2014).

AML is also a cancer that originates in the bone marrow, in this case blood cells are made at too high a rate and the immature cells do not develop into fully functioning cells. Most often, too many immature white blood cells are produced which crowd the bone marrow and circulate throughout the body while not functioning as they should. AML is most commonly diagnosed in people over the age of 65 and is usually treated via chemotherapy

although both radiotherapy and transplant may be considered. Survival rates for AML are poor with only 12% surviving beyond five years (CRUK, 2014).

CML is a form of chronic leukaemia that originates from the overproduction of granulocytes, a type of white blood cell, that do not fully mature. Over time, the granulocytes collect in the spleen, causing enlargement, and the bone marrow preventing the production of healthy blood cells. CML is most common in adults over the age of 50 and has varied survival rates; if caught early and a bone marrow transplant is undertaken, survival may be 15 years or more. If the patient is in the blast phase (the acute phase where blast cells make up more than 20% of the blood or bone marrow) at diagnosis, survival may be only months. Imatinib is the most common treatment for CML although, dependent upon stage of disease, transplantation and chemotherapy may also be considered.

Finally, CLL is a chronic form of leukaemia. CLL develops slowly and, when also taking the incurable nature of the illness into account, many people do not receive immediate treatment for their CLL but rather may be monitored via 'watch and wait' for months or even years. In CLL, the body makes too many lymphocytes that do not fully mature and build up over time in the lymphatic system. This causes enlargement of the lymph nodes and also affects production of healthy blood cells as the bone marrow becomes overcrowded. Once the patient becomes symptomatic and treatment is required, options include chemotherapy and stem cell transplantation. CLL is predominantly a disease that affects older adults, being most common in people over the age of 65.

Lymphoma

Lymphoma is a cancer of the lymphatic system that can be broken down into two broad categories: Hodgkin lymphoma (HL) and Non-Hodgkin lymphoma (NHL). NHL is the most commonly diagnosed haematological cancer and is the sixth most commonly diagnosed cancer in the UK (CRUK, 2013) and the 12th most common cause of death from cancer (CRUK, 2013). Survival rates of NHL have improved, with 63.4% of patients surviving five or more years after diagnosis. There are many subtypes of NHL; broadly grouped into B-Cell type or T-Cell type, dependent upon the type of cell in which the cancer originates; B-Cell lymphoma is far more common than T-Cell lymphoma. As with haematological cancers more generally, NHL can either be highly aggressive or more indolent and slow growing in nature. The type of cancer and how fast it is likely to grow influences treatment decisions, indolent NHL can be monitored via watch and wait until symptoms present but

symptomatic or aggressive NHL can be treated by chemotherapy, radiotherapy or biological agents. NHL is more common in the over 50s age group (CRUK, 2013).

HL is less common, accounting for 0.6% of cancer cases in the UK (CRUK, 2013) and 0.2% of cancer deaths. The survival rates for HL are higher than NHL with 83.2% of patients surviving five or more years post diagnosis (CRUK, 2013). HL accounts for around 20% of all lymphoma diagnoses (Macmillan, 2011). HL can be differentiated from NHL as, when examined under the microscope, the Reed-Sternberg cell is present in the lymph nodes. The Reed-Sternberg cell is a type of white blood cell that has become cancerous, and prevents other white blood cells from fulfilling their normal role (i.e. to make antibodies to fight infection in the body). HL has two diagnosis peaks: in young adults and the over 50s. Generally, treatment for HL is by chemotherapy and survival rates are good with over 80% living for over five years post-diagnosis.

Myeloma

Myeloma is the least common type of haematological malignancy, accounting for 1.4% of cancer cases in the UK (CRUK, 2013). It is an incurable diagnosis and accounts for 1.7% of cancer deaths with only 37% of patients surviving beyond five years after diagnosis. In myeloma, large numbers of abnormal plasma cells are produced. These myeloma cells produce large amounts of an abnormal antibody (paraprotein) which cannot effectively fight infection and interferes with normal antibody production. The myeloma cells can also spread throughout the bone marrow and can affect healthy bones causing bone-thinning and associated pain and fractures. As with CLL and certain types of NHL, myeloma can be monitored via watch and wait rather than requiring immediate treatment if the patient is asymptomatic. Where active treatment is required, chemotherapy is most commonly used. Myeloma incidence increases with age and less than 30% of patients will survive longer than five years.

Key differences in comparison with other cancer groups

Haematological cancers display several key differences to solid tumours such as breast, lung or colorectal cancer. There are pathological differences (Lakhani et al., 2004) that can affect treatment type, but, perhaps more importantly for patients, these differences translate into differences in the organisation of services and there is a clear degree of separation from those services aimed at solid tumours (NICE, 2003).

Patients diagnosed with a haematological malignancy are more likely to be cared for by a smaller team of healthcare professionals (HCPs). For some, diagnosis and subsequent

treatment decisions are made by a single clinician rather than the multidisciplinary decision making seen elsewhere: whether or not this is a negative aspect of haematology treatment is not clear, but it does allow for continuity for the patient and for an on-going relationship to be forged with their Consultant. Patients with a haematological cancer have also been identified as being less likely to access palliative care services than patients with a solid tumour (Howell et al., 2010). This may well relate to the fact that haematology patients are cared for by a smaller, more consistent team of HCPs who may feel that they then know the patient and their needs and are best placed to continue care at end of life. Alternatively, it is possible that this is an access issue due to the small numbers of individuals affected. Whether or not this results in any differences in the support services available to haematology patients, in terms of resulting referrals, is not clear.

The number of haematology referrals into a clinic is typically low when compared to the numbers seen within oncology clinics, perhaps a factor in the tendency to have consistent relationships between patient and clinician. While this may enable a more supportive environment for a patient, dependent upon the patient-HCP relationship, the lack of external input into patient care may result in a reduced number of services becoming available to haematology patients. The comparatively low number of palliative care referrals has been highlighted, but national statistics regarding the number of haematology patients who access psychological support services, occupational therapy services or make use of charity-led support programmes has not been forthcoming.

Cumulatively, the differences between haematological malignancies and the solid tumours in which the majority of psychosocial oncology research is conducted makes it difficult to predict the extent to which parallels can be drawn between the two groups. It is logical that where considerable differences exist between two patient groups, that there will also be differences in the type and prevalence of unmet need and in their psychological wellbeing. A key aim of this thesis is to explore the unmet needs of haematological cancer patients and to expand the currently limited evidence base related to the psychological wellbeing of this group.

Distress and cancer

That distress is common in those with a diagnosis of cancer is a phenomenon that has been relatively well explored and is certainly not a new concept within the cancer literature. Previous research indicates that the overall prevalence rate for distress in cancer patients is

between 35.1% (Zabora et al., 2001) and figures as high as 75% (Jacobsen et al., 2007), a significant proportion of patients. Distress in this context generally relates to the presence of psychological morbidity as measured by an assessment tool. Anxiety and depression are commonly highlighted within the psycho-oncology literature (Ibbotson et al., 1994; Carroll et al., 1993) but post-traumatic stress disorder, adjustment disorders and changes to a person's personality and their perceptions of their world can also be affected (Smith et al., 1999; Mitchell et al., 2011). Each disorder has its own specific challenges for patients but all ultimately impact upon a person's experiences and their overall wellbeing. Understanding distress in all forms in people with cancer would facilitate better care for patients and would allow for the relationship between distress and both the precipitating and resulting factors to be better examined. A brief overview of some of the most common forms of distress in cancer is presented below.

Anxiety

Anxiety in and of itself is not unusual and will affect most people to some degree at some point in their lives. Upon being diagnosed with cancer, however, the normal presence of anxiety in reaction to a threatening situation can become prolonged, thereby negatively impacting upon quality of life (Brown et al., 2010). Research has indicated that 13% of patients will experience clinically significant levels of anxiety (Aass et al., 1997) as assessed by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Anxiety was more prevalent in hospitalised patients and in women when compared to men within this study. In women with breast cancer, the prevalence of anxiety has been found to be slightly higher at 16% (Luboonthavatchai, 2007). One study that included lymphoma patients found that 48% of patients reported sufficient levels of anxiety for an anxiety disorder to be considered and a diagnostic clinical interview to be carried out (Stark et al., 2002).

The presence of anxiety in cancer patients can create distinct challenges for the medical professionals involved in caring for patients and who are: (a) not trained in managing mental health; and, (b) not confident in their ability to distinguish between normal levels of anxiety that may come with being diagnosed and treated for cancer and clinically significant anxiety (Stark & House, 2000). There is also the innate difficulty in deciding what clinically significant anxiety actually is given that the diagnosis relies on the presence of the anxiety of being disproportionate to the level of threat. As cancer represents the ultimate threat to many people, the potential threat to life, what qualifies as disproportionate is not necessarily clear.

Depression

Along with anxiety, depression is one of the more commonly cited psychological disorders seen in people living with cancer. Depression is a mental disorder that impacts upon a person's mood and can affect the ability to gain pleasure from usual activities, sleep, appetite and cognitive abilities (American Psychiatric Association, 2013). As with anxiety, some impact on mood can be expected when receiving a life threatening diagnosis, however, it is essential that patients and healthcare professionals are able to recognise what is normal and when extra support to help manage low mood is required.

Depression has received attention as a potential predictor of cancer incidence (Spiegel et al., 2003) yet findings have been inconclusive. More established is the relationship between depression, and also anxiety, in predicting disease progression and mortality. Meta-analysis has indicated that there are reasonable grounds to believe that the presence of depression directly influences mortality, but studies of this type are unable to make a statistical association with disease progression (Satin et al., 2009). Depression has also been linked to pain levels and quality of life in cancer patients (Spiegel et al., 2006; Hulbert-Williams et al., 2012). Those with high pain levels were found to be more likely to also have depression. Whether the increased level of pain is instrumental in the development of depression or whether those with depression are more likely to report pain is unclear. In addition, associations have been made between depression and quality of life in cancer patients (Hulbert-Williams et al., 2012) with levels of depression being significantly associated with later levels of quality of life.

PTSD

Post-traumatic stress disorder (PTSD) is a psychiatric illness that is associated with a change in psychological wellbeing after a traumatic event (APA, 2013). Precipitating traumatic events can include life-threatening illness, such as cancer, and results in a range of symptoms that include changes in mood, a heightened state of arousal, intrusive thoughts relating to the traumatic event and changes in behaviour (APA, 2013). PTSD is less common in cancer patients than anxiety or depression with estimates of prevalence at 3-4% in early stage patients and up to 35% in patients who were assessed post-treatment (Gurevich et al., 2002). These statistics relate to a clinical diagnosis of PTSD as required by the DSM-IV-TR, however, incidence of relevant symptoms that do not meet the full diagnostic criteria are much higher, at up to 80% in patients post-treatment (Gurevich et al., 2002).

Research on PTSD in cancer has been conducted across a variety of cancer diagnoses, but there has been a specific focus on the haematological cancer, notably in the case of patients who require bone-marrow transplantation. Studies of PTSD in patients with haematological malignancies have estimated prevalence to be from 8% in NHL to 17% in post bone marrow transplantation patients (Smith et al., 2008; Black et al., 2005). A potential correlation between physical functioning and PTSD symptomology has been found in this group (DuHamel et al., 2001). In patients with poorer levels of physical functioning, any type of change was associated with greater incidence of PTSD symptomology.

The Everyday Impact of Cancer

While anxiety, depression and PTSD are commonly cited in the psycho-oncology literature and have formed the basis of psychological intervention (Sheard & Maguire, 1999; Jacobsen et al., 2008), the absence of clinically significant levels of distress does not necessarily mean that the person does not need support to help them come to terms with their diagnosis and subsequent life changes. Being diagnosed with cancer affects multiple aspects of a person's life and their sense of self, all of which have the potential to impact upon a person's psychological wellbeing. Appearance can often be affected as a result of the intensive treatment required to manage cancer, leading to body image concerns (Hopwood, 2003). While there are ways of assessing the impact cancer has on body image (Hopwood, 2003), this is not something that is typically explored with patients in the clinic setting. Higher levels of body image concerns have been associated with: treatment type; weight change; pain; fatigue; and anxiety (Rosenberg et al., 2013). Change in body image is important as it has been found to correlate with overall quality of life. In men diagnosed with prostate cancer (Taylor-Ford et al., 2013) and in women with breast cancer there is a link to overall psychological distress (Helms et al., 2008). In patients diagnosed with haematological cancer, research has implied that patient's body image and the way in which they perceive their body becomes altered (Weber et al., 2001). Perceptions of control related to their bodies were also decreased yet emotional constructs were comparatively high indicating that a diagnosis of haematological cancer results in feelings of loss of control of one's own body and has a high emotional impact. Changes to the body as a result of treatment are likely to be seen as outside of the patient's own locus of control and may exacerbate any feelings of loss of control which may further impact upon the perceptions that a person has of themselves and can ultimately feed back into the overall presence of distress.

Cancer can not only affect the relationship that a person has with themselves, but also how they relate to those close to them. A diagnosis of cancer is not only potentially distressing for the person diagnosed, but their family and friends also have to confront the possibility of losing a loved one. Clinically significant distress is not only more prevalent in those diagnosed with cancer, but increased levels of anxiety and depression have also been highlighted in partners (e.g. Grov et al., 2005). In addition, the very fabric of relationships and how a couple relates to each other can be altered. Changes in body image, along with the potential for pain and discomfort as a result of the diagnosis, can impact upon sexual relationships (e.g. Takahashi et al., 2008; Badr et al., 2009). The notably intensive nature of the treatments often required by patients with haematological cancer can also bring with it specific challenges for family and friends; with many taking on caregiver roles (Beattie & Lebel, 2011), bringing an entirely new dynamic to a relationship. Interestingly, in the caregivers of patients due to undergo stem cell transplantation, caregiver distress was found to be at its highest pre-transplant (Beattie & Lebel, 2011) which may be indicative of concerns about the impact of the treatment on their loved one and how their relationship may change as a result, however, the reality is easier to manage. Carer wellbeing can be important within the context of the wellbeing of the patient as it has been shown that interpersonal relationships can impact upon how well a person copes with significant life events, serious illness included (Bloom et al., 2001: Holland & Hollahan, 2003).

Ultimately, being diagnosed with cancer and the changes that such a diagnosis can bring, can impact on a person's perception of who they are, their identity. Living through cancer may force a person to create a new sense of self which can impact upon their overall wellbeing and the way in which they relate to the world. Little is known about how patients ultimately end up viewing themselves (Park et al., 2009) but words such as 'survivor', 'patient' and 'victim' were all endorsed in the paper by Park. Each would bring with it a different view of the world and associated feelings about their experiences. Throughout the experience of being diagnosed and treated, it may be that identity is a constantly evolving concept, and it is also possible that those who are more adaptable may be better suited to incorporate these changes into their perceptions and expectations. A degree of caution must be taken however, when attaching fighting language to cancer patients. There is an emerging literature that suggesting that the military metaphors so often used in connection with cancer (fighting, battling, war) are not well received by patients. The British Medical Journal (BMJ) has now published two papers (Wiggins, 2012; Berger, 2014) exploring the use of such terminology in connection to cancer. While the

goal of such language is to motivate, to unite both patient and clinician against a common enemy, there is a danger that creating the illusion of a battle being fought places the locus of control solely with the patient. 'Thinking positively', does have associated benefits in terms of increased motivation and adherence, yet cannot fundamentally cure the patient from cancer. If a patient does not achieve remission or experiences a relapse, then it is not because they have lost some psychological test of will against the cancer (Coyne et al., 2007) yet there is a danger that creating this perception will result in patients feeling like they could have tried harder somehow.

Screening for distress in cancer

In 2009, the International Psycho-Oncology Society (IPOS) unanimously endorsed the concept of distress as a sixth vital sign in cancer settings and subsequently proposed screening for distress to be a recognised IPOS strategy in 2010 (Watson & Bultz, 2010), publishing their Standard of Quality Cancer Care (Holland, Watson & Dunn, 2011). In essence, this proposes that distress should be considered alongside temperature, respiration, heart rate, blood pressure and pain to be a fundamental aspect of patient wellbeing and should be assessed as such (Bultz & Carlson, 2005). Since this time, distress as the sixth vital sign has been endorsed by several UK based charities such as Breast Cancer Care, the British Psychosocial Oncology Society and Macmillan Cancer Support. Recognising that the presence of distress can be as important to patients as aspects of their physical wellbeing is crucial and the endorsement by both national and international organisations promotes awareness within the medical setting and provides an indication of the perceived importance of distress.

Given the proven presence of distress in a subset of those living with a diagnosis of cancer, it is important to have a method of accurately detecting distress in its various forms. Generally speaking, there are assessment tools to measure levels of clinically significant distress for each different disorder. Commonly used examples are the Hospital Anxiety and Depression Scale (HADS) for anxiety and depression (Zigmond & Snaith, 1983); the Mental Adjustment to Cancer (MAC) scale (Watson et al., 1988), for adjustment in people with cancer; and the EORTC QLQ C30 (Aaronson et al., 1993) to assess quality of life in people with cancer. While by no means exhaustive, this list represents some of the most commonly used tools within both research and clinical settings.

Despite the growing recognition within the research literature that distress can significantly impact upon a patient's wellbeing and their recovery, screening for the presence of distress

within the clinical setting has witnessed slower uptake. The debate around whether or not to routinely screen patients has been one that has been fiercely contested by those working within the field of psycho-oncology (Coyne, 2013). Those who advocate the use of screening maintain that screening improves patient-professional communication and increases the likelihood of a referral to psychosocial support services being made (Mitchell, 2013) while its opponents emphasise the lack of a conclusive link between screening and patient benefit and the potential for services to become 'rationed' (Coyne, 2013). Regardless of the differences in opinion regarding screening, for maximised effectiveness, screening must be delivered by those adequately trained to do so, be conducted in a manner that is acceptable to patients and there must be adequate resources available to support those shown to be in need (Mitchell, 2013). If a healthcare professional is going to screen for the presence of distress in patients with cancer, then they must also have the ability to make appropriate referrals to resources already in place to support that patient. This will only be successful if the hospital or clinic has someone in post who is able to undertake a full assessment if the need arises, usually a mental health professional, and have access to further support services. Without this system in place, screening may serve to aid communication between patient and professional but would not fulfil its purpose of improving access to psychological support thus potentially leaving a patient dissatisfied.

If the very purpose of assessing for the presence of distress is to then be able to refer patients on to support services, the question of acceptability must be raised. Even where the presence of distress is indicated by an assessment tool, the support being proposed must be both wanted by and acceptable to the patient. Previous research has suggested that only 36% of distressed cancer patients express a desire for help with their distress (Baker-Glenn et al., 2011). This highlights the need to understand exactly where patient's support needs lie in order to be better able to target acceptable support services to those most in need.

Human Need

The concept of need is well established within the field of psychology and the wider health-related literature. In 1943, Abraham Maslow set out his now famous Hierarchy of Need which theorised that people are motivated by need, ranging from basic needs such as physiological need, the need for safety and the need to be loved, moving on to needs that are required for growth, or as Maslow defined it, self-actualisation. A deficiency in need was thought to provide people with the motivation to act, for example, if hungry, to go and

find food. In order for higher needs to be met, the lower, basic needs must be met first. Doyal and Gough proposed the Theory of Human Need (1991), stating, like Maslow, that basic health needs are of prime importance and that, when these health needs are threatened, they must take precedence over what were termed autonomous needs (Doyal & Gough, 1991). At their core, health needs are centred around avoiding harm to our person and therefore as humans, we behave accordingly.

Both theories place need as a deviation from a desired state of being and a person's actual state of being. They place human need as highly individual, with the ultimate aim to be able to become a fully-functioning and contributing member of society, providing a sense of belonging. The presence of need is indicative of potential harm and therefore people strive to ensure that needs are met, and goals can therefore be achieved.

The diagnosis of a major illness such as cancer poses the ultimate threat to the most basic health needs, life versus death. While people have ongoing unmet needs relating to their illness, these theories postulate that patients will be unable to fully achieve psychological wellbeing. This approach is limited in that there is no clear standard of health desired by all. Need and desires are ultimately subjective, therefore, it is difficult to apply any constants or standards to need theory that would allow for a universal understanding of what a basic level of need is.

Psychosocial needs within cancer

People diagnosed with cancer, including those with a haematological cancer, can have a range of unmet needs. Unmet psychosocial needs refer to the presence of a desire for help or support that relates to a person's emotional or psychological wellbeing (Boyes et al., 2009; Watson et al., 2012). It is this desire for support that differentiates an unmet need from the presence of distress or patient concern where there may be no wish for external assistance to combat the issue in question. Unmet needs can relate to psychological concerns such as the presence of anxiety or depression, or the wish to see a healthcare professional as a result of these concerns. They can also relate to the social aspects of illness such as the impact upon relationships, or the practical for example the impact that cancer has on a person's employment. Unmet needs assessment directly measures the patient's own desire for help with psychosocial concerns rather than assessing for the presence of distress or other issues without determining whether the patient wishes for the concern to be addressed. This is an important distinction when considering the distinct concepts of need and unmet need. Need alone does not imply a desire for help. Accurate

and routine assessment of unmet patient needs is central to ensuring that appropriate supportive care is provided (Zucca er al., 2014) and in order to identify deficits in current care provision. In a healthcare system with limited resources this enables the provision of supportive care services to be tailored towards those who have identified themselves as needing help.

Assessment of patient need and assessment of patient distress are often similar in format and in how they are carried out within the clinical setting. Indeed, the Holistic Needs Assessment (NCSI, 2013) is an increasingly common way of assessing overall patient wellbeing within the clinic setting in UK hospitals. The two concepts are likely to be connected in more ways than simply similar methods of detection; the presence of high levels of unmet psychosocial need is indicative of patient need for support in areas of their life relating to the psychological and emotional wellbeing and is, therefore, likely to have a direct link to the presence of distress (Armes et al., 2009; Morrison et al., 2012). Indeed, previous research has indicated that anxiety is more common in those with higher levels of unmet need (Cull et al., 1995). Conversely, it may be that the presence of distress is the underlying cause of the presence of need, and that those who are more significantly affected by their diagnosis are more likely to seek support. While the precise relationship is not currently understood within the relevant literature, it seems likely that one does exist and that assessing patient wellbeing in this way may be more acceptable in format for patients. As such, researching unmet needs within patients groups has the potential to impact upon patient wellbeing in three distinct ways. Firstly, an unmet needs assessment provides immediate information to the care team with regards to where a patient feels that they would benefit from the provision of extra support. Secondly, the relationship between unmet need and psychological outcomes, if proven, means that unmet needs assessment has the potential to act as a screening measure for overall wellbeing and distress. Finally, if we are able to identify that there is a predictive relationship between unmet needs and psychological wellbeing, then there is the potential to develop preventative interventions that will meet patient need and reduce the subsequent negative impact on wellbeing. In addition, this type of assessment may be more acceptable to both patients and their clinicians who can feel a lack of confidence in addressing formal psychological concerns in their patients (Moorey, 2013). The research presented in this thesis is linked to implementation and clinical relevance, as opposed to being removed from the practicalities of providing supportive care for cancer patients.

Previous research into unmet need in general cancer groups has categorised type of need into overarching subgroups of need, for example: psychologic; health system and information; physical and daily living; patient care and support; and sexuality (Sanson-Fisher et al., 2000). Further exploration of unmet need within cancer is undertaken in Chapter Two.

Specific needs of different patient groups

As a group of cancers, haematological malignancies have received comparatively little empirical attention within the literature when compared with more common diagnoses (Paul et al., 2011). Within psycho-oncology research, there has been a tendency for the majority of the literature to be conducted with patients diagnosed with breast cancer and, therefore, women. The existing research relating to unmet psychosocial needs has often been conducted on either mixed diagnostic samples or samples of breast, lung or prostate cancer patients (Harrison et al., 2009). Research relating to rarer patient groups is needed as these patients are typically less well recognised by charities and, therefore, available research funding is often smaller in scale (National Cancer Institute, 2014). In addition, the psychological wellbeing of men living with cancer is also less well understood at present and warrants further exploration.

Instinctively, it would seem probable that differences in the unmet needs of men and women exist yet this is still to be fully explored within the literature. Previous research relating to women with a diagnosis of breast cancer found that level of unmet needs remained relatively stable over time and that the most commonly identified unmet needs were patient education, counselling and alternative treatment options (Von Heyman-Horan et al., 2013). Education, the lack of a partner, and the presence of anxiety all contributed to the presence of unmet needs within this sample. Other research carried out with this patient group indicated that while the presence of needs remains over time, the nature of the needs identified changes (Park & Hwang, 2012). Initially, needs in all domains (with the exception of sexuality) were noted but as patients moved into the first three years of survival, needs relating to psychological and information came to the fore. Again, the presence of needs was related to psychological wellbeing with unmet needs being significantly associated with depression and quality of life. Similar research on men with prostate cancer has found that needs relating to care were deemed most important and that support needs, while rated as being most unmet, were deemed less important (Boberg et al., 2003). This indicates a potential contrast with the unmet needs identified by female

samples who identified counselling and psychological needs as relevant. In cancer carers, women report higher levels of distress than their male counterparts, possibly due to an increased perceived burden of care (Perz et al., 2011), again suggesting that women are more likely to report psychological distress relating to a cancer diagnosis. There are also recognised age related differences in the level of distress associated with a diagnosis of cancer with those who are younger at the time of diagnosis typically displaying higher levels of anxiety and depression (Linden et al., 2012). This large scale study fed into the already developing understanding that younger patients and women are both at higher risk of psychological distress as a result of cancer.

In addition to variations in unmet needs according to age and gender, there are differences in the reported unmet needs of different ethnic groups. In a US based study, women of Latina origin reported higher levels of unmet information and care needs than women of other ethnic groups (Janz et al., 2008). Research comparing the unmet needs of female German and Chinese cancer patients found that Chinese women were more likely to report the presence of unmet need than German women (Lam et al., 2011), yet more German women reported the presence of anxiety and depression than Chinese women. In a similar study comparing the needs of American and Egyptian cancer patients, again, there were differences found in the type of needs most commonly identified (Ali et al., 1993). The most commonly reported unmet need in the American sample was the need for information while the Egyptian sample reported relief from dependency as being the most important.

There are clear differences in the type of unmet needs reported by different demographic groups, whether they be gender, age or culture dependent. Specific areas of need emerge within each subgroup that seem to be of notable importance to that particular group. Given that there are innate differences between cancer diagnoses as well as the clinical demographics of patients, it seems likely that the type of needs identified would also be variable between cancer diagnoses. Haematological cancers differ from all other solid tumours in their presentation, treatment type and the environment in which care is provided. The specific challenges that accompany a diagnosis of haematological cancer will be discussed as an on-going theme within this thesis: the systematic review in Chapter 2 syntheses what is already known in the literature and Chapters 3, 4 and 5 employ empirical mixed methods research to better understand the link with distress outcomes.

Psychological Flexibility

People who are more adaptable, who therefore may be better suited to incorporate change into their perceptions of the world and their expectations of their own lives, may also be less likely to experience cancer as a highly negative event or to have high levels of unmet need. Within contextual behavioural science, adaptability is paralleled with being more psychologically flexible, a concept that has been defined as being made up of two separate processes: acceptance of experience and a commitment to values-based behaviour (Hayes, Luoma, Bond, Masuda & Lillis, 2006). In essence, psychological flexibility is the ability to connect with the overall context of a situation and to be able to continue to behave in such a way as to be in line with one's own life aims and values. It is proposed that psychological flexibility should be viewed as fundamental to psychological health (Fledderus et al., 2013) and that the ability to adapt, to shift mind-set when a situation compromises functional or emotional wellbeing, to maintain balance and to remain committed to deeply held life values holds more importance to overall wellbeing than the more traditional concepts of the satisfaction of basic psychological needs or positive thinking (Kashdan, 2010). If this holds true and people who are more psychologically flexible also enjoy higher levels of psychological wellbeing, then this concept may be influential in the maintenance of wellbeing during cancer.

Not all patients who receive a cancer diagnosis experience a negative psychological impact and it has been postulated that those who are able to maintain positive wellbeing and are those people who are more likely to adopt values-based behaviours and live according to their own identified values (Ciarrochi & Bailey, 2008). Those who are more easily able to accept negative life events and maintain their ability to live according to their life values are also more likely to adapt successfully to a diagnosis of an illness such as cancer and to experience less emotional consequences of unmet psychosocial needs than patients for whom a diagnosis carries a profound negative impact. Having an unmet psychosocial need implies a desire for help or support in order to maintain one's psychological wellbeing: those who are more psychologically flexible may be better able to generate their own internal support and therefore able to view their diagnosis within the greater context of their lives to accept the life changes that a diagnosis such as cancer can bring, regardless of whether they identify as having unmet psychosocial needs or not. If psychological flexibility is more important to psychological health than whether or not a person's psychological needs are met, then this concept may have real importance for how the impact of unmet psychosocial needs are interpreted in the context of their impact on

psychological wellbeing. Chapter 5 of this thesis explores how psychological flexibility relates to both unmet need and psychological wellbeing in haematological cancer survivorship.

Thesis Aims

The evidence base relating to unmet psychosocial needs is currently typically focussed on the identification of type of need within specific patient groups. While this holds real value in being able to accurately identify where patients feel that they require additional support and can be easily translated through into clinical practice, as research it is somewhat descriptive and does not provide any real insight into the psychological processes or mechanisms of change that might be involved in the maintenance of psychological wellbeing during the cancer experience. More information is needed regarding the evolution of unmet needs over time, and whether or not this is common within differing cancer diagnoses. There are indications within the existing literature that a relationship between unmet needs and psychological morbidity in cancer patients exists, however, this relationship has not been well defined in any great depth nor has it been explored within patients with a haematological diagnosis. In addition to being able to accurately define the relationship between unmet need and wellbeing, we need to be able to understand the mechanisms that are active within the relationship and to define them within an overarching psychological framework.

Understanding process allows for the development of interventions that are targeted towards the mechanisms that are active in maintaining psychological wellbeing, as such making them more efficient and effective. If an intervention can be tailored so that it acts on concepts that are influential in maintaining wellbeing and does not target concepts that do not ultimately improve distress, then interventions can be honed and streamlined, essential in an environment of limited healthcare resources. This PhD aims to undertake a psychological exploration of need within haematological cancer to provide the necessary information and knowledge for such application.

This thesis aims to address the following questions:

1. ***What is the current evidence base regarding the unmet psychosocial needs of haematological cancer patients and where do the gaps in our knowledge lie?***

2. ***What do haematological cancer patients perceive to be their key areas of psychosocial needs and why were those specific needs important during the patient experience of cancer?***

3. ***What are the unmet psychosocial needs and psychological outcomes of newly diagnosed patients and are these two concepts related?***

4. ***What are the long term psychosocial needs of haematological cancer survivors and does the concept of psychological flexibility moderate the relationship between need and psychological wellbeing?***

These aims will be met by employing a mixed methods approach over a series of four separate but related studies. Question 1 will be addressed by a systematic review of the existing literature relating to unmet needs in this patient group. Following this a qualitative study of patient experiences of need will address Question 2 and build upon the knowledge gained from the systematic review. Subsequently, Questions 3 and 4 will be met by conducting quantitative assessments of need and psychological morbidity in patients with a diagnosis of haematological cancer making use of the knowledge gained in the preceding studies.

Mixed methods research approaches have particular value and utility when conducting research and as such have gained in popularity in recent years (Johnson & Onwuegbuzie, 2004). Mixed methods research can traditionally be viewed as belonging within the pragmatic paradigm, that is when the research question becomes central and the 'what' and 'how' of that specific problem take the fore (Mackenzie & Knipe, 2006), however, the use of multiple methods can also fit within the transformative paradigm where it can be viewed as enabling the researcher to view the world through multiple lenses or viewpoints. It is now common for researchers to view qualitative and quantitative research as complementary, allowing them to adopt the most appropriate method of data collection and analysis for their particular research question (Creswell, 2003).

Proponents of mixed methods research argue that it enables a more comprehensive approach to addressing a research question than either qualitative or quantitative research alone (Newman, Ridenour, Newman, & DeMarco, 2003). It has been asserted that there are five reasons to conduct mixed methods research and that all studies within this

paradigm can be categorised as fitting within one or more of the following five aims (Greene, Caracelli & Graham, 1989): triangulation; complementarity; development; initiation; and expansion. This thesis can be viewed as adopting a mixed methods approach for reasons of triangulation, development and expansion as the unmet needs of haematology patients will be examined in all four studies. This will enable the identification of clear patterns of unmet need across different samples with shared diagnoses to add weight to the assertion that specific areas of need are particularly relevant to haematology patients (triangulation). The studies included within this thesis were developed and undertaken sequentially to allow knowledge from each study to inform subsequent work (development). Finally, in each subsequent study, the breadth and depth of the research question will be expanded with the different methods each being employed to answer specific aims within the overall research question (expansion). Employing multiple methodological perspectives will allow for a deeper explanation of the phenomena under investigation. In addition, this thesis takes a critical perspective, exploring the challenges of conducting research both within psycho-oncology in general and in haematological oncology more specifically.

Chapter 2 - Unmet Psychosocial Needs in Haematological Cancer: A Systematic Review

Overview

The literature review included within Chapter 1 highlighted that a diagnosis of cancer can have a significant impact upon both psychological and emotional wellbeing. This review of the literature concluded in a number of research aims being identified that would facilitate the expansion of existing knowledge and develop our understanding of the unmet psychosocial needs and psychological wellbeing of haematological cancer patients. This chapter will seek to address the first thesis question of what is currently understood about type of unmet psychosocial need that affects people with a diagnosis of haematological cancer via a systematic review. Identification of both type and prevalence of the psychosocial needs most relevant to those diagnosed and treated for this group of cancers in order to be able effectively to target and implement appropriate support services. A systematic review was conducted to examine, in depth, the existing evidence base. Prior to this systematic review, the literature relating to unmet psychosocial needs within this patient group had not been collated or appraised, despite this being an important step in developing a clear understanding of psychosocial need in haematological malignancy. This review was designed to act both as a standalone research project, and to create a knowledge baseline from which later stages of this PhD project could build.

What does the literature tell us about unmet psychosocial needs in cancer?

Patient-centred care has become the gold standard in the provision of healthcare across the UK and beyond. Provision of care should no longer focus solely on the delivery of medical treatment, but should also look to encompass the person's psychological and social needs in order to fully support that person's emotional and psychological wellbeing throughout their illness (NICE, 2004).

For the purposes of this study, the term psychosocial needs relates to the needs that underlie a person's emotional and psychological wellbeing. A need can be thought of a something that is required (Carlson, Waller, & Mitchell, 2012; Watson et al., 2012),

something that is important to the person. Psychosocial needs are a relatively broad category of need that can encompass issues such as identity, body image, spirituality, relationships and social support mechanisms or the more practical issues related to a person's illness (Sanson-Fisher et al., 2000). The types of needs within this category are diverse and far reaching, having the potential to impact upon all areas of a person's life. It is understood that needs of this nature are often underreported to treating clinicians (Wen & Gustafson, 2004), and, therefore, have the potential to be left unacknowledged and the patient without assistance in their area of need.

If psychosocial needs are defined as the needs that underlie a person's psychological and emotional wellbeing, then their importance becomes clear when we look at the impact that a negative psychological response to illness can have upon prognosis. The presence of anxiety, depression and a poor quality of life have all been found to negatively impact upon a variety of treatment outcomes: from adherence to treatment, motivation, ability to cope with the diagnosis and on prognosis (Hemingway & Marmot, 1999).

The existing literature on psychosocial need within cancer populations has highlighted that needs are prevalent and that currently, there are still areas of need that are not being adequately catered for. Levels of unmet psychosocial need have consistently been found to be affected by age, gender, psychiatric history, marital status, treatment type and socioeconomic status (Puts, Papoutsis, Springall, & Tourangeau, 2012). Previous research has indicated that both type and prevalence of need differs between individuals and across time. Increased levels of need have been previously identified in those who are younger, female, unmarried, indicate a past psychiatric history or current problems in this area, have a poor QoL, physical difficulties, whose disease is already at an advanced stage at the time of diagnosis, those with a low income, financial difficulties or who live in rural areas (Hodgkinson, Butow, Hunt, & Wain, 2006).

Harrison and colleagues (2009) systematically reviewed literature that looked at unmet needs across a general cancer sample found that the type and prevalence of need differ across time points within the cancer journey. The largest proportion of studies identified focused on needs within the treatment phase indicating that this is where the majority of the research is currently centred. Specific needs relating to the diagnosis phase, post-treatment phase and advanced and palliative care phase were also noted. It is worth noting that, in the context of this systematic review, none of the papers included within the Harrison review were specific to haematology and therefore it was not possible to use this

work as a guide for how the level of unmet needs may evolve during this specific type of illness.

The majority of studies on unmet needs have reported results based on mixed samples with fewer looking specifically at a single diagnosis. While this does make the findings applicable to larger groups of people, needs that are specific to a particular diagnosis are difficult to distinguish and the variation between methods makes comparison between studies challenging (Harrison, Young, Price, Butow, & Solomon, 2009). Where the existing literature serves the function of highlighting a range of needs that are commonly found across different diagnoses, in order for research to become fully applicable to a haematology setting r, an understanding of whether or not the same type of unmet psychosocial needs are present and relevant is required.

Categorisation of Need

Types of need and the way in which they are categorised can differ between both needs assessment tools and the research articles in which they are reported (Armes et al., 2009; Bonevski et al., 2000; Tamburini et al., 2000). Needs may span multiple categories or be categorised differently by different researchers or clinicians. This has implications both when considering the types of need relevant to a patient group and for this review.

Psychosocial needs are diverse and far reaching. There is now a recognition that high quality care must take into account all aspects of wellbeing, not just the physical. However, the ways in which needs are recognised and understood can differ dramatically both across members of the same profession and between the various professions that are involved in patient care. The emphasis and nature of a person's background may impact upon how they understand psychosocial need and the importance that is afforded to them. A medically trained oncology consultant for example, may well have a very different perspective to the counsellor or the occupational therapist, all of whom may be treating the same patient.

The International Psycho-Oncology Society (IPOS) has published its Standard of Quality Cancer Care (Holland, Watson, & Dunn, 2011), this is an international quality standard to support the development and implementation of new clinical practice guidelines. There are two aspects to the Standard of Quality Cancer Care:

1. Quality cancer care today must integrate the psychosocial domain into routine care;

2. Distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiration and pain.

IPOS has requested that cancer organisations around the world act to endorse their standards to address supportive care issues for cancer patients and their families. In the UK, the British Psycho-Oncology Society (BPOS), Cancer Focus Northern Ireland and Macmillan Cancer Support have all signed up to endorse these standards of care.

Disparity between definitions of psychosocial need is also seen within the academic world and in the literature that has been published on the subject. For the purposes of this thesis, the term psychosocial needs is being used to describe any needs that could be described as impacting upon a person's psychological or emotional wellbeing. In other publications however, alternative terms such as supportive care needs (Armes et al., 2009; Harrison, et al., 2009), perceived needs (Boyes et al, 2006), unmet needs (Lobb et al., 2009) or simply needs (Clavarino, Lowe, Carmont, & Balanda, 2002) are used, all of which refer to the same concepts and ideas in relation to the unfulfilled requirements of people with a cancer diagnosis. In addition, some studies have focussed on investigating a specific area within the type of needs currently being discussed. Information needs have often been highlighted as a particular area of interest (Hammond et al., 2008; Hawkins et al., 2008; Jenkins, Fallowfield, & Saul, 2001).

This impacted upon the way in which the search string was derived for this systematic review: for broadest applicability, all aspects relating to the concept of psychosocial need were taken into account and included within the search strategy. The danger of conducting a systematic review where the central concept is defined so variably is that the search strategy will not be sensitive enough to highlight all relevant papers whilst remaining specific enough to ensure that the number of irrelevant papers screened is kept to a minimum (Montori, Wilczynski, Morgan, Haynes, & Hedges, 2005). In order to minimise this risk, the search string was designed based upon terms used in previous relevant publications. Past papers were examined to see how need was defined in both the abstract and the key words. In addition, the reference lists of included papers were also searched for any further relevant papers that had not been selected by the original search.

Measurement of Need

Psychosocial needs are measured via the use of self-report needs assessment tools; clinically relevant measures that are used in clinical populations to measure and assess type and level of needs and their importance to the patient in the context of that individuals'

lifestyle and circumstance. Their aim is to assist in the collection of information about the patient; these tools can be viewed as being key to developing clinicians' understanding of what is important to their patient and, therefore, their ability to deliver high quality, person-centred care. Over the past 30 years, there has been an increase in the number of needs assessment tools being developed for use in cancer populations (Boyes, Girgis, & Lecathelinais, 2009; Hodgkinson, Butow, Hobbs, et al., 2007; Hodgkinson, Butow, Hunt, et al., 2007) and at present, in part due to the commitment of the Department of Health to support this area, there is an interest in taking this further. Research has indicated that patients would welcome questions regarding the psychosocial aspects of their illness (Hack, Degner, Parker, & Team, 2005) but that, at present, the way in which this task is approached by healthcare professionals is often unsystematic at best, and in some cases absent entirely. Both healthcare professionals and patients vary considerably in both their ability and desire to talk about psychosocial issues. Patients can feel unsure about approaching their clinical team about issues that are perceived as not directly relevant to their illness (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000) or that their problems are an unavoidable consequence of their diagnosis and therefore it would be pointless to address them.

Recent NICE guidelines have indicated that assessment of a person's needs should be the first step in the provision of supportive care and appropriate services (NICE, 2004) and has proved influential in the development of needs assessment here in the UK. Assessment of need should not be a one-time event but rather should be part of a flexible, evolving approach to a person's care that reflects a person's current needs and requirements (Watson, et al., 2012). Incorporating routine psychosocial needs assessment into patient care allows for a more tailored approach to treating patients and allows patients the opportunity to discuss their needs with their clinical team. Specific assessment tools and issues relating to their implementation will be discussed further in Chapter Three of this thesis.

How will this review help to further knowledge and understanding?

Haematological cancers stand slightly apart from other cancer diagnoses in a variety of ways. Previous findings have indicated that the manner and the setting in which haematological malignancies are treated can differ from that in solid tumours. Those diagnosed with a haematological cancer are less likely to be treated in a palliative care setting (NCIN, 2011; McGrath & Joske, 2002) than patients with other diagnoses and more generally, treatment in the UK is commonly carried out in district general hospitals, or

satellite units, rather than in larger specialist cancer centres. As such they may not have all of the same resources available to them. Those treated with a blood cancer are still more likely to die in a hospital and the proportion of patients for whom this is a reality is falling more slowly than for other cancer diagnoses (NCIN, 2011). The reasons behind the underdeveloped link between haematology and palliative care is not clear, however it could be due to a range of factors. It may be that care tends to remain within the team that have treated the patient throughout the course of their illness, that teams 'take care of their own', or it may be that haematological malignancies are viewed as being slightly apart from other diagnoses and that some preconception is playing a role, or that the nature of the illness means that transitions are too sudden meaning that there is little time for palliative input (Ansell et al., 2007; Howell et al., 2011; Manitta, Philip, & Cole-Sinclair, 2010). It is clear that the difference between treatment of curative and palliative intent is either not well understood or poorly implemented.

Regardless of the causes of the differences between haematological and solid malignancies, the fact that these differences exist brings with it the possibility that these two patient groups will have distinct and separate types of unmet psychosocial needs. Until the literature has been examined in greater depth than has occurred to date, it is unclear firstly, if differences in need exist, and secondly, if there is a difference in need, what the needs most relevant to haematological cancer patients are.

What were the aims of the review?

This systematic review was designed to collate the literature relating to unmet psychosocial needs in patients with a diagnosis of haematological cancer, answering Thesis Question 1:

1. ***What is the current evidence base regarding the unmet psychosocial needs of haematological cancer patients and where do the gaps in our knowledge lie?***

Secondary study objectives aimed to fulfil the following:

- To produce information regarding the type and prevalence of unmet psychosocial needs in haematological cancer;
- To gain an understanding of the information regarding need that is available to clinicians working in oncology;
- To highlight any gaps within the current literature;
- To create a baseline for further projects within the PhD.

This systematic review is the first to explore unmet psychosocial needs in haematological cancer. The previous work conducted within this area has focused on either solid tumours or mixed cancer samples. Prior to this systematic review, the literature relating to levels of unmet psychosocial need in haematological cancer had not been systematically collated and analysed as a whole. The result being that there has to date existed a gap in our knowledge of psychosocial need in haematology and bringing this understanding in line with that which exists for other, more common cancer diagnoses.

Methodology

The Literature Search

Key psychological and medical databases were selected based upon them being the sources most likely to contain articles of the type being searched for and permitting a multiprofessional focus to the review. This review focussed only on published literature, it was felt that searching both medical and psychological databases and journals would bring up studies that were most relevant to the research question. The following databases were included: CINAHL, MEDLINE, PsychINFO, Web of Knowledge, COCHRANE and DARE. EMBASE was excluded from this review as it has a biomedical basis and is especially strong in it its coverage of drug and pharmaceutical research which was not felt to be consistent with the aims of the review. All databases were searched using the search string presented below.

Alongside the database searches, the archives of key journals were hand searched for relevant papers. The journals chosen were Psycho-Oncology, British Journal of Cancer and Journal of Psychosocial Oncology. These three journals are well respected within their fields, with both good impact factors and high relevance to the area of research. As with the chosen databases, the journals covered aspects of both psychological and cancer literatures and preliminary scoping searches conducted prior to the commencement of the systematic review indicated that these journals were all relevant to this review. Due to the time constraints associated with conducting this review as part of a PhD project, it was felt that these three journals would offer the greatest likelihood of containing relevant papers whilst remaining practicable within the time limits available. All databases and journal archives were searched during a ten day period between the 2nd and 12th January 2012.

In addition to the searches defined above, the reference lists of all articles meeting inclusion criteria were searched for any additional relevant articles that had not been selected by the search strategy within the original search. As the literature in print relating to psychosocial needs in haematology is small, it was felt that any other relevant papers were highly likely to be included within reference lists of the papers collated from the databases and journal searches.

Search Strategy

The search strategy was designed to strike a balance between targeting only the most relevant papers while simultaneously not being so specific as to risk potentially excluding

pertinent articles (Montori, et al., 2005; Wilczynski, Haynes, & Hedges, 2007). The terms used in the search strategy were determined by consideration of the research question and by the corresponding aims of the review combined with looking to past papers that had been published in relevant areas to identify both the key words and definitions of terms most commonly used.

Three areas were identified as being key to the research question: 'haematological cancer', 'psychosocial' and 'unmet needs'. Each of these three terms were considered to be central to the research question and were therefore expanded into a list of synonymous search terms with the aid of previous literature. These terms were then used to make up the search strategy in order to ensure that all relevant articles would be selected by the search strategy as the terms used within the search string may be used as either a key word or be present within the abstract of relevant articles.

The following search string was developed and inputted into the selected databases as follows:

Haematological Cancer

1. (cancer OR neoplasm$ OR malig$)
2. H*em$
3. 1 AND 2
4. blood cancer
5. leukaemia
6. lymphoma
7. myeloma
8. 3 or 4 or 5 or 6 or 7

Psychosocial

1. psychosocial
2. psychologic$
3. social
4. emotional
5. adjustment
6. adaptation
7. supportive
8. information
9. communication
10. practical
11. spiritual
12. health
13. identity
14. coping

15. body image
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15

Unmet Need / Outcomes

1. unmet AND need
2. distress
3. anxiety
4. depression
5. quality of life
6. psychosocial AND need
7. supportive AND care
8. help-seeking
9. need$ AND assessment
10. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9

Study Selection

In order for a paper to be included within the review, it had to fulfil the following inclusion criteria, taking into account the PICOS system (Sayers, 2008) for defining inclusion criteria (population, intervention, comparators, outcomes and study design):

- Studies must include an assessment of unmet psychosocial need.
- Studies must be conducted with an adult sample with participants over the age of 18.
- The sample must be, at least in part, comprised of patients with a diagnosis of haematological cancer.
- All studies must have been conducted within an appropriate healthcare or community setting, studies conducted within inpatient psychiatric or forensic institution were not eligible for inclusion due to the potential bias relating to the cause of need.
- Reporting of need must be via direct patient report and not via a family member or healthcare professional.

There were no restrictions placed upon the proportion of the sample which had to be made up of patients with a haematological malignancy. Additionally, there were no restrictions placed on the point of the cancer journey at which needs were to be assessed or the time point at which needs were reported. Given that a key aim of the review was to quantify type and prevalence of unmet need, qualitative studies were not included in the analysis.

The following flow chart presents the number of studies at each stage of the systematic review and reasons for exclusion.

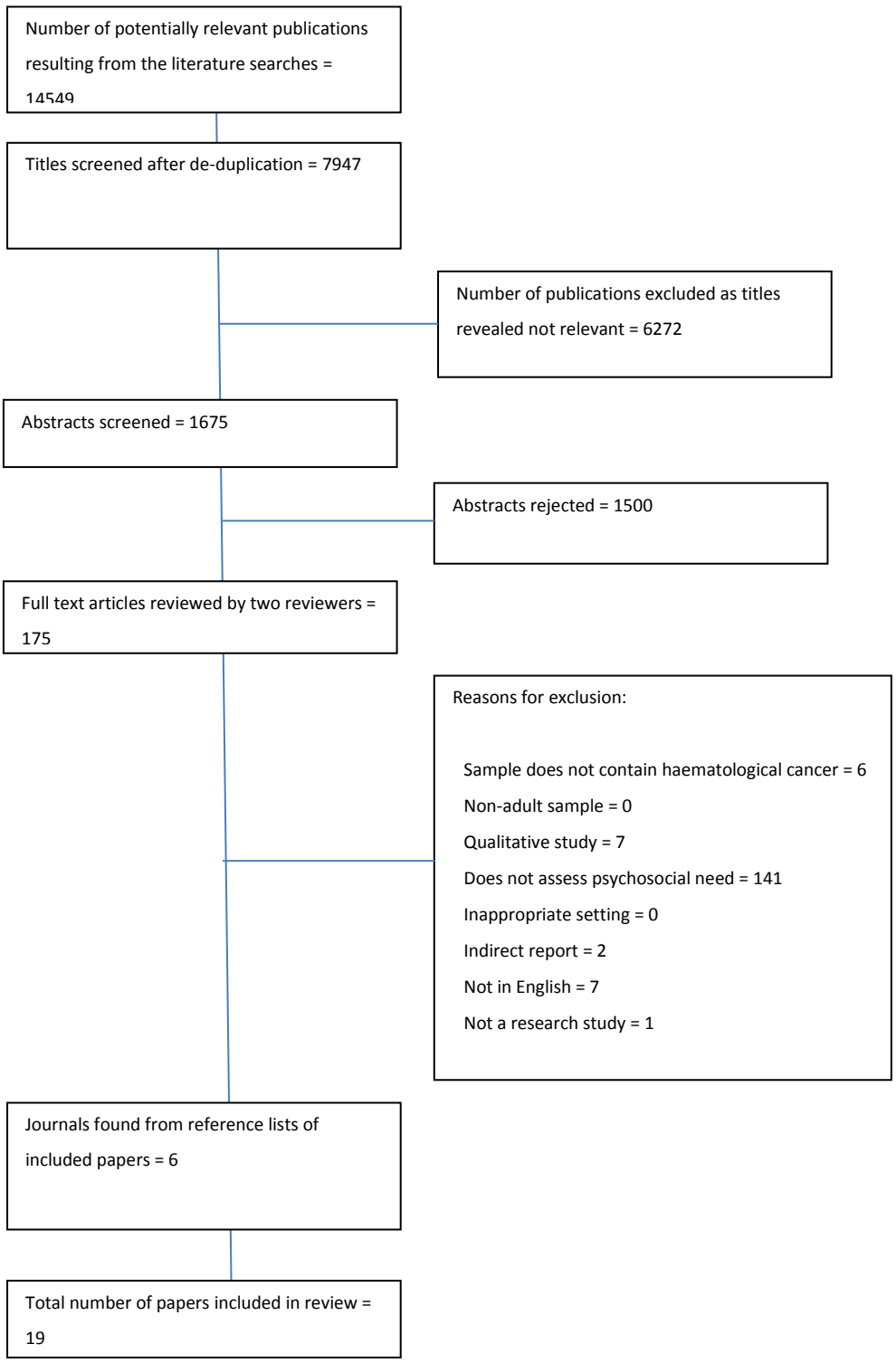

Figure 2.1: Flow diagram of results

Once all searches had been completed, all references were exported into EndNote and then de-duplicated. The inclusion assessment was comprised of three stages. Initially, the complete collection of references was visually screened to exclude any papers that obviously did not fit the criteria. Secondly, the abstracts of the remaining papers were read and compared to the pre-defined inclusion criteria, any papers that did not meet the inclusion criteria were excluded. Finally, all remaining papers were read in full and assessed against the inclusion criteria. The final stage of the inclusion assessment was double screened by an independent second reviewer in order to ensure that no relevant papers were discarded and to exclude any possibility of the presence of bias within the study. In the case of any disagreements regarding the inclusion or exclusion of a study, the academic supervisor acted as moderator.

Data Extraction

Once the inclusion assessment was complete, data was extracted from all studies selected for inclusion with the aid of a standardised form (see appendix 1). For each study, the following information was gathered:

- A brief summary of the study: author, date, publishing journal, identification number.
- A description of the sample: recruitment, size, inclusion and exclusion criteria.
- Information about the design of the study: setting, timings, interventions.
- Outcome measures.
- Method of analysis.
- An evaluation of the work: limitations, implications for future work or clinical practice.
- Any comments: author, reviewer.

At the same time as data extraction was undertaken, each paper was assessed against a quality assessment checklist (Kmet et al, 2004). The quality assessment checklist was taken from the paper published by Kmet and colleagues in an attempt to create standardised, empirically grounded quality assessment criteria for use when evaluating research papers. There are a range of quality assessment checklists that have been created for use within systematic reviews (Oxman, 1994; Shea et al., 2007), however, the criteria developed by Kmet were designed to be applicable to a diverse range of studies, not just randomised control trials. As this was expected to be the case with the studies included in this systematic review, this quality assessment checklist was deemed the most suitable.

Both qualitative and quantitative criteria were generated by the Kmet et al tool paper. To suit the purposes of this review, only the criteria for use with quantitative research papers were used. For each item in the checklist, a response and relating score was determined: yes (2), partial (1) or no (0) as recommended in the Kmet paper. An examination of the quality of included studies is an important component of a systematic review as it allows the reader to consider how trustworthy or reliable to findings being presented can be considered to be (The Cochrane Collaboration, 2002). Provided that a study has met all of the inclusion criteria, then a poor quality score would not mean that the study is discounted, rather this provided contextual information to be discussed within the narrative synthesis of the results.

Synthesis of Results

While a meta-analysis can be viewed as the 'gold-standard' of data synthesis within systematic reviewing, the data extracted in this review precluded the use of meta-analysis. Narrative synthesis (Popay et al., 2006) was selected as the method of handling the data gathered and of combining the results of the studies. Of the papers included in the review, there were five papers reporting the results of four separate studies that shared a common needs assessment measure and the time-point at which needs were assessed. Some consideration was given to conducting a small-scale meta-analysis as a sub-section of the results; however, it was felt that this sample size was too small for the production of reliable results (Rosenthal, 1995; Papworth & Milne, 2001; Field, 2001). There is some debate within the literature concerning meta-analysis as to how many studies are required for the generation of reliable results, however, five studies were not likely to provide results that were stable enough to provide a reliable estimate of population variances and that the probability of a Type I error was too great (Field, 2003).

Prior to synthesising the results, the first step of a narrative synthesis is to tabulate the included studies (Popay et al., 2006). Two tables were drawn up: the first compiled information of each of the studies including study date, sample, design, needs assessment and key findings; the second summarised the results of the quality assessment process and highlighted particular strengths and weaknesses of each study. Presenting the information in a clear yet detailed manner is beneficial in that it allows for transparency in the methods (Petticrew & Roberts, 2006; Smith, Devane, Begley, & Clarke, 2011) and makes it clear how the reviewer went about appraising the study data. Having the data presented in this way paves the way for the reviewer to begin the synthesis of the results.

Organisation of studies is the second stage of the narrative synthesis process. Having the data tabulated prior to attempting to organise the studies helps to clarify both the context and contribution of each study which is invaluable when deciding how to organise studies into meaningful categories. For this review, in order to be better able to investigate the presence of psychosocial needs in a meaningful way, studies were organised according to whether the sample was a mixed cancer sample or focussed on haematological cancer only. This was to allow for differentiation between needs expressed solely with those with the diagnosis of the research question, or needs that may reflect a wider population. Within the mixed or haematological only categories, papers were organised according to the time-point at which unmet psychosocial needs were assessed. The time-points were identified based on those used successfully in previous literature (Harrison et al, 2009; McIllmurray et al, 2001; Soothill et al, 2004) and were: at diagnosis; during treatment; at the end of treatment; into survivorship; with the additional category for study that assessed needs across a sample of participants at differing time-points.

After the studies are organised into appropriate categories, the next stage of conducting a narrative synthesis is to complete a 'within study analysis' or a preliminary synthesis. This stage of the synthesis process seeks to provide a narrative description of each of the studies included in the systematic review to include an account of the quality assessment and its outcomes. As the results of the within study synthesis can be viewed as being the preliminary stage of the overall synthesis, a further stage of narrative synthesis is required to develop the findings and to further examine emerging trends.

The final stage of the narrative synthesis, the between study analysis, seeks to generate an overall account of the evidence, to encompass an exploration of the differences between the included studies and their findings and of any factors that may have impacted upon how widely applicable the results are deemed to be (Popay et al., 2006). The key aim of the between study synthesis is to explore the relationships within the data. Variations in outcomes, methods, samples, settings and so on should be examined. Within the narrative synthesis, the quality of all included studies must be reflected upon when considering the overall quality and robustness of the results.

Results

This review includes the results of 18 studies written up as 19 separate publications. For each of the studies included in the review, data was extracted from each paper according to the process detailed in the methodology section.

A summary of the key data extracted is presented in Table 2.1 and quality assessment data in Table 2.2. An example of the study data extraction form can be found within the appendices (Appendix 1).

Study Characteristics and Study Quality

The quality of the included studies was generally good, the mean quality score was 82.9 and the median quality score was 88.3. This is likely to be due, at least in part, to the fact that the scope of this review was limited to published studies. This means that all of the studies included in this systematic review have been peer assessed and found to be of an acceptable standard for publication within academic journals.

There were several issues to arise from the data extracted from the studies included within the review. One such problem concerning the way in which the data could be analysed was the lack of a consistent needs assessment tool. Of the 18 different studies included in this review, 11 different needs assessment tools were used. Four studies used the Supportive Care Needs Survey (SCNS) to assess unmet need in participants, two studies used the Cancer Survivors Unmet Needs assessment (CaSUN) and five papers reporting four studies used the Patient Needs Inventory (PNI) as their measure. Of the remaining eight studies, each used a different measure with three studies using a measure that they had designed specifically for use within their study. This leads to problems with generalisability between the results of different studies as in each different measure, the way in which psychosocial needs are categorised and the method of assessment of the presence of unmet need will differ.

Sampling was another key issue identified within the review. Four of the studies were deemed to have a small sample size (Boyes et al., 2006; Clavarino et al., 2002; Lobb et al., 2009; Molassiotis et al., 2011), with other studies identifying recruitment bias (Soothill et al., 2001; Soothill et al., 2004) or a sample of convenience (Armes et al., 2009). Across the reviewed papers, there are differences in the specific haematological cancer diagnoses included and variations in the time-point at which needs was assessed. When combined with samples with the identified weaknesses, it may be that in places the results lack

weight due to methodological limitations and small sample sizes. Two of the studies that were deemed to have a small sample size were two of the three studies that used haematology specific samples thus meaning that the total number of participants with haematological cancer diagnoses is comparatively small, limiting the generalisability of the findings presented within this review.

Table 2.1: Summary of data extracted from each included study.

Author	Year	Country	Source	Sample	Sample size	Measure	Key Findings
Armes et al	2009	UK	Journal of Clinical Oncology	Mixed cancer diagnoses currently receiving treatment	1152	SCNS	66% expressed few or no needs at baseline, 69% expressed few or no needs at follow up. Most frequently reported needs at both time points were psychological needs and fear of recurrence.
Ashbury et al	1998	Canada	Journal of Pain and Symptom Management	Mixed cancer diagnoses who have received treatment within last two years	913	Designed for study	Fatigue and anxiety most commonly reported symptoms.
Boyes et al	2006	Australia	European Journal of Cancer Care	Mixed cancer diagnoses attending clinic for first consultation	80	SCNS	Psychological needs most commonly reported.

Clavarino et al	2002	Australia	Australian Journal of Rural Health	Mixed cancer diagnoses currently receiving treatment	28	SCNS	Psychological needs most commonly reported. Fear of recurrence (42.9%) and concerns about the worries of those close to you (50%) most common unmet needs in patient group
Hammond et al	2008	USA	Fertility and Sterility	NHL patients in survivorship phase.	250	Information needs questionnaire	61% of young people expressed the need for information about fertility.
Hawkins et al	2008	USA	Journal of Psychosocial Oncology	Mixed cancer diagnoses with a recent diagnosis	731	Designed for study	Information needs in areas of social, lifestyle and financial concerns identified. Also required more information regarding long-term implications.
Jenkins et al	2001	UK	British Journal of Cancer	Mixed cancer diagnoses having regular consultations.	2331	Adaptation of Cassileth's Information Needs	87% preferred to have as much information as possible.

						questionnaire	
Liang et al	1990	Australia	British Journal of Cancer	Mixed cancer diagnoses currently receiving treatment	188	Designed for study	Family was reported as the highest need, followed by dealing with emotional stress.
Lobb et al	2009	Australia	Patient Education and Counselling	Haematological cancer diagnosis who had completed treatment	113	CaSUN	Most frequently endorsed need was the need to feel as though I am managing my health together with the medical team, the most frequent unmet need was fear of recurrence.
McDowell et al	2010	Australia	Psycho-Oncology	Mixed cancer diagnoses	438	SCNS-SF34	Unmet needs decrease over time since diagnosis. Unmet needs at diagnosis predict later presence of unmet needs.
McIllmurray et al	2001/2003	UK	European Journal of	Mixed cancer diagnoses	402	PNI	Needs relating to health professionals most

			Cancer Care / Palliative Medicine				commonly expressed. Information and support networks also common areas. Found that religion was related to fewer unmet needs. Highest percentages of unmet needs related to health professionals and identity.
Mesters et al	2001	Netherlands	Patient Education and Counselling	Mixed cancer diagnoses	498	PINQ	A need for information about disease and treatment was the strongest theme.
Molassiotis et al	2011	UK	Psycho-Oncology	Multiple Myeloma patients	132	CaSUN	Highest reported need was for more accessible hospital parking, followed by insurance and then fear of recurrence.
Preyde et al	2010	Canada	Journal of Psychosocial	Mixed cancer diagnoses currently	156	ESAS, CES-D and Perceived	Fear of recurrence main need identified.

			Oncology	receiving treatment		Social Support Scale	
Sollner et al	2001	Austria	British Journal of Cancer	Mixed cancer diagnoses currently receiving treatment	298	Hornheide Questionnaire, Questionnaire to Assess the Need for Psychosocial Support	20% of participants expressed an urgent need for psychotherapeutic support, 14.7% expressed an urgent need for counselling by a social worker.
Soothill et al	2001	UK	Supportive Care in Cancer	Mixed cancer diagnoses	295	PNI	4.4% of sample had 10+ significant unmet needs. Confidence in healthcare professionals most commonly rated as important or very important. Most common unmet needs were help with financial matters, help filling out forms, help with anger and opportunities to meet people in the same situation.

Soothill et al	2003	UK	European Journal of Oncology Nursing	Mixed cancer diagnoses	233	PNI	Most common patient reported unmet needs: help with financial matters; help filling out forms; help with dealing with anger. Majority of patient-carer pairs expressed importance of good relationships with healthcare professionals and good quality information.
Soothill et al	2004	UK	Journal of Psychosocial Oncology	Mixed cancer diagnoses	380	PNI	Found that patterns of psychosocial need differ between distinct patient groups.

Table 2.2: Study quality

Study	Year	Strengths	Weaknesses	Quality Score
Armes et al	2009	Large sample size. Included a follow up assessment. Used recognised needs assessment tool.	Convenience sample used. Does not report results according to diagnosis.	20/22 90.1%
Ashbury et al	1998	Large sample size.	Measure developed for use in study. Variation in clinical demographics – stage etc. Aspects of the study not well defined. Needs not well defined.	14/22 63.6%
Boyes et al	2006	Recognised needs assessment tool used.	Small sample size. High attrition rate.	24/26 92.3%
Clavarino et al	2002	Recognised needs assessment tool used.	Small sample size. Not all sample paired. Poorly defined methods.	12/22 54.5%
Hammond et al	2008	Specific to haematological cancer.	Poorly defined report. Poorly defined measure used.	15/22 68.2%
Hawkins et al	2008	Large sample size.	Some clinical information missing.	18/22

			Study part of a larger study – unclear what larger study was investigating. Measure developed for use within study.	81.8%
Jenkins et al	2001	Used recognised assessment tool. Large sample size. Well defined.	Specific to information needs.	21/22 95.4%
Liang et al	1990	Looks at concerns specific to diagnosis. Clearly defined looking at psychosocial need.	Unclear how measure used was validated. General areas of need investigated, lacks specifics.	18/22 81.8%
Lobb et al	2009	Solid analysis. Specific to haematological cancer. Recognised needs assessment tool used.	Relatively small sample size. Not all clinical information known. Variations in stage and time.	21/22 95.4%
McDowell et al	2010	Recognised needs assessment used. Longitudinal design.	Limited information provided regarding sample.	20/22 90.1%
McIllmurray et al	2001	Clearly defined. Recognised measure used. Broken down according to diagnosis and stage.	Low response rate.	22/22 100%
McIllmurray et al	2003	Clearly defined.	Low response rate.	22/22

		Recognised measure used		100%
Mesters et al	2001	Solid analysis.	Focus of the study on validating the measure not on needs assessment. Only part of the study included patients with a haematological malignancy.	20/22 90.1%
Molassiotis et al	2011	Recognised needs assessment tool used. Specific to haematological cancer. Clearly defined. Looks at one diagnosis only.	Relatively small sample.	22/22 100%
Preyde et al	2010	23% of sample haematological cancer.	Clinical details missing. Small sample size. Questionnaires used.	14/22 63.6%
Sollner et al	2001	Solid analysis.	Some clinical information not known. Not assessed over time.	20/22 90.1%
Soothill et al	2001	Recognised needs assessment measure used.	Recruitment bias identified. Low response rate. Weaknesses in report detail.	16/22 72.3%

Soothill et al	2003	Recognised needs assessment measure used.	Level of demographic information reported. Analysis methodology could be more explicit.	17/22 77.2%
Soothill et al	2004	Recognised needs assessment measure used.	Recruitment bias identified. Low response rate.	19/22 86.4%

An area where several studies scored poorly in the quality assessment was in the quality and level of detail of their reporting. Where studies designed their own needs assessment tool, it was often not clear enough how the resulting tool was assessed for psychometric robustness and suitability for its intended use. In some instances, the particular focus of a paper meant that other aspects of the work were neglected, for example, in the study conducted by Mesters and colleagues (2001), the focus of the paper was on the validation of their measure and as a result the level of detail surrounding the assessment of need was reduced. In other work, the level of detail provided regarding the clinical data of participants was less than it might have been (Lobb et al, 2009; Preyde et al, 2010; Sollner et al, 2001). While it is appreciated that each of the papers included within a review was written for publication within an academic journal and therefore is likely to have adhered to a pre-determined word limit, the quality of reporting, overall, could have been improved.

Due to the type of studies included in this review, that is where a specific outcome is assessed within pre-defined patient groups, random allocation and interventional blinding was generally not applicable. This reflects the methodologies used and was not deemed to negatively impact upon the quality of the included works.

Results of Individual Studies

Included studies were categorised according to both sample and time point at which needs were assessed. Initially, studies were organised into mixed cancer samples and haematology only samples. Within these categories, studies were organised according to whether needs were assessed at diagnosis, during treatment, at the end of treatment, into survivorship or at mixed time points. The studies are categorised and shown below.

Mixed Diagnoses

Two studies were identified where participants were recruited at diagnosis:

- Boyes et al., 2006 - This study was a questionnaire study that assessed needs using a truncated version of the SCNS. For each item, participants rated their perceived level of need between none and high. The most commonly reported needs in both the control and intervention groups were psychological needs and in both of these groups psychological needs were found to decrease over time. Indeed, needs across all areas were found to decrease as time passed since diagnosis. This study scored well on the quality assessment, scoring 92.35, lending credence to the

results. The use of a recognised needs assessment tool was deemed to be a positive, however, the sample size was small and the attrition rate was high.

- Hawkins et al., 2008 - This paper described a questionnaire study where participants rated their needs on a Likert scale from 1 to 5. The study highlighted that participants identify needs for more information about whether treatment will work (63.1%), being able to have children (62.5%) and paying for care (59.2%) as their most pressing cause for concern. The study was not clear on the precise measure used to assess needs in participants. This study scored 81.8% on the quality assessment, indicating a good level of study quality. Drawbacks highlighted included the use of a novel assessment measure and lack of clarity regarding the aims and objectives of the larger project of which this study was a part.

Studies where participants were recruited during treatment in a mixed sample:

- Armes et al., 2009 - This paper reports a questionnaire survey where psychosocial needs were assessed using the SCNS. Need for help was rated on a 5 point scale from none (0) to high (5). The highest rated needs at both time points within the study were psychological: fear of the cancer spreading (30% at baseline, 26% at follow up), concerns about the worries of those close to you (26% at baseline) and uncertainty about the future (26% at baseline, 20% at follow up). The results indicated a general trend of needs decreasing in the time between baseline and follow up. A high score was obtained by this study on the quality assessment at 90.1%.

- Clavarino et al., 2002 - This paper outlines a questionnaire study using the SCNS to assess level of need. Levels of need are rated between 1 and 5. The highest reported needs by patients were psychological: concerns about the worries of those close to you (50%), fears about the cancer returning (42.9%). 7 items of high need came from the psychological domain. This study achieved the lowest score on the quality assessment, scoring on 54.5%, therefore indicating these results to be the least reliable of the studies included within the review.

- Liang et al., 1990 - This paper reports on a questionnaire survey that assessed unmet need using a measure designed for use within this study. Items on the

assessment tool measure broad areas of need rather than specific concerns. Participants were asked to rate area of need between 1 (low) and 8 (high) according to how much worry resulted from the need. Overall, it was found that family was the area associated with highest levels of need. Family was also the highest need reported by participants with a diagnosis of lymphoma. Participants with lymphoma reported higher levels of need in the areas of sex and work in comparison to other diagnoses and reported the lowest levels of needs in relation to stress. This study received a good score on the quality assessment, 81.8%, however, was marked down on the use of a non-validated needs assessment measure.

- Jenkins et al., 2001 - This study focussed specifically on the assessment of information needs. It was designed as a questionnaire survey using an adaption of Cassileth's Information Needs Questionnaire. Most commonly reported absolute need was whether or not it is cancer (60%) and what are the possible side effects of treatment (60%). This study received an excellent score in the quality assessment, 95.4%, indicating a high quality level.

- Preyde et al., 2010 - A questionnaire study using the ESAS, CES-D and Perceived Social Support Scale. Fear of recurrence was the main need identified. This study scored comparatively poorly in the quality assessment, receiving 63.6%.

- Sollner et al., 2001 - A questionnaire study using the Hornheide Questionnaire and the Questionnaire to Assess the Need for Psychosocial Support as measures to assess unmet needs. As the name of the measure suggests, this study focussed specifically on need for formal psychosocial support rather than a general assessment of need. The study found that 20% of patients expressed an urgent need for psychotherapeutic support and 14.7% expressed an urgent need for counselling by a social worker. In addition, oncologists were found to significantly under-estimate the level of need experienced by patients. A solid quality assessment score of 90.1% was obtained by this study.

Studies where participants were recruited at the end of treatment:

- Ashbury et al., 1998 - A questionnaire study using a measure specifically developed for use within the study. Participants were asked to rate questions on Likert scales. Fatigue (78%) and anxiety (77%) were the most common issues identified. Weaknesses in the measure used and the way in which aspects of the study were defined meant that this study received a relatively low quality assessment score of 63.6%.

There were no studies identified that assessed need at the survivorship time-point in a mixed sample.

Several studies were found that recruited participants from varying time-points:

- McDowell et al., 2010 - This study was designed as a longitudinal survey design that utilised the SCNS-SF34, a shortened version of the SCNS, to assess psychosocial need. Needs were measured across a five point scale as with other studies previously described that used the SCNS to assess need. The three most commonly reported needs were lack of energy/tiredness, not being able to do the things you used to and fears about the cancer spreading, needs which spanned the physical and psychological domains. The general trend across the sample was that needs decreased over time. This study achieved a solid quality assessment score of 90.1%.

- McIllmurray et al., 2001 and McIllmurray et al., 2003 - Two papers reported a questionnaire study that used the PNI to assess need. Needs were rated on a scale of 1 to 5 of how important they were felt to be. Needs relating to health professionals and support network most commonly rated highly. (Note – the PNI does not have a psychological needs section.) These publications scored the maximum scores in their quality assessments, 100%, indicating that this research is of an excellent quality.

- Mesters et al., 2001 - A study involving interviews that were quantitatively analysed and needs assessed using the PINQ. It was found that participants identified needs relating to information about disease and treatment. This study was restricted for the purposes of this analysis by the fact that only part of the

study included haematology patients but a solid design meant that a quality assessment score of 90.1% was achieved.

- Soothill et al., 2001 - A cross-sectional survey study that used the PNI to assess unmet needs in participants. Needs are rated on a scale from 1 (low) to 5 (high) according to how important they are. The most common needs reported as being important are confidence in health professionals (94%) and health professionals who have time to discuss issues with me (92%). The needs most commonly reported as being unmet however, were help with financial matters (35%) and help with filling out forms (24%). Recruitment bias, low response rate and some weaknesses in the report detail impacted upon the quality assessment score received at 72.3%.

- Soothill et al., 2003 - A cross-sectional questionnaire survey of both cancer patients and their carers. Needs were assessed using the PNI. The need most often rated as important for both patient and carer was confidence in the health professionals that I meet (88.8%) followed by honest information (88.4%). The most important need for patients but not carers were help with any distressing symptoms (29.2%), help with transport (28.8.5) and help with any fears (27%). The most commonly reported unmet needs for patients were help with financial matters (40%), help with filling out forms (28%) and help with my anger (20%) however, these were all rated comparatively low in terms of their importance to patients. Weaknesses in the amount of detail reported lowered the quality assessment score, however a good score of 72.3% was still achieved.

- Soothill et al., 2004 - A cross-sectional questionnaire study using the PNI to assess needs. Unmet needs were broken down according to sub-groups of patients organised according to response patterns for their unmet needs. Unmet needs relating to information of health professionals had the highest probability of being present in the largest number of sub-groups. A good quality assessment score of 86.4% was achieved, let down by recruitment bias and low response rates.

Haematological Cancer Only

No studies were identified where participants were recruited at the diagnosis time point in a haematology-only sample.

One study was identified at the treatment time-point:

- Molassiotis et al., 2011 - A cross-sectional questionnaire study using the CaSUN to assess needs. Patients with multiple myeloma made up participants within sample. The most commonly reported needs were more accessible hospital parking (10.6%), help with life or travel insurance (10.4%) and help to manage concerns about the myeloma coming back (7.9%). This study achieved a perfect quality assessment score of 100% indicating a high level of quality of this research.

One study was identified that recruited participants at the end of treatment:

- Lobb et al., 2009 - A questionnaire study using the CaSUN to assess unmet needs. The sample included patients who had been diagnosed and treated for any haematological malignancy. The most frequently reported unmet needs were help to manage my concerns about the cancer coming back (42%), the need for an on-going case manager to whom I can go and find out about services whenever they are needed (33%) and the need to know that doctors talk to each other to coordinate my care (31%). This study achieved an excellent quality assessment score of 95.4%.

One study was identified that recruited participants in the survivorship phase:

- Hammond et al., 2008 - A questionnaire study using an Information Needs Questionnaire (INQ). The sample for this study included patients with NHL only. This study looked specifically at the information needs of patients with NHL and found that 61% of young people expressed the need for information about fertility. This paper achieved a comparatively poor quality assessment score at 68.2% which was due to poor definition of both the measure used and the results more generally.

Synthesis of Results

Results of mixed sample studies

The results from the mixed samples indicate a range of key areas of need. Psychological needs, where measured, were typically scored highly. Within the area of psychological need, fear of recurrence was identified as the single most commonly identified unmet need. Needs relating to health professionals were scored highly within the studies that used the Patient Needs Inventory (PNI) to assess need. It is worth noting, however, that the PNI does not have a category dedicated to the assessment of psychological need, therefore we cannot determine how important this set of participants would have rated needs of this type to be in relation to their own needs. Information needs were another area that was highlighted within the studies conducted with mixed cancer samples. Fatigue was identified as a key concern in two studies.

Results of haematology only studies

Within the haematology only samples, two key areas of need were identified. Fear of recurrence was identified in two out of the three studies and the third paper identified a need for information about fertility in younger patients as a key finding.

Commonalities between mixed and haematology only samples

Overall, when considering the needs raised in both samples, fear of recurrence and information needs were the most consistently identified. Explaining similarities between groups according to time-point: at diagnosis, there were no studies identified in the haematology only sample with which to form a comparison with the mixed diagnoses sample. In studies conducted when participants were receiving treatment for their diagnosis, fear of recurrence was raised in both sample groups. While fear of recurrence was highlighted in both groups, it is worth noting that in the haematology only study, this was only the third most commonly expressed need and that other needs were rated more highly. However, this is the result of a single study and the dataset therefore is too small to make firm conclusions. Only one study was identified in either group where patients had been recruited during survivorship, meaning that it was not possible to draw comparisons between groups here.

There is some suggestion that fertility issues are important to this patient group. While there is not a wealth of data relating to fertility, as a theme it emerged within both the mixed and haematology only samples. In the mixed sample, not being able to have a child

was highlighted and in the haematology only sample, an unmet need for more information relating to fertility was identified.

Differences between mixed and haematology only samples

While there have been several similarities highlighted between the mixed cancer sample and the haematology only sample, there are also a number of differences that merit exploration. The first difference to note is that none of the studies identified with a haematology specific sample were longitudinal in design. It is not possible therefore to form any comparisons with the apparent trend in the mixed sample group where the level of unmet needs decreases over time.

At diagnosis, again it is not possible to form comparisons between groups as no studies were identified at this time-point in the haematology only sample. Within the mixed sample, psychological needs emerged as being the most prevalent yet we have no information as to whether this trend is also seen in haematological cancer patients at the time of diagnosis.

At the treatment time-point, unmet practical needs were highlighted within the haematology only sample but were not found to be present in the mixed cancer samples. Additionally, at the same time-point, in the mixed sample, concerns about those close to you was repeatedly expressed yet this was not raised within the haematology only sample.

There were fewer studies published at the end of treatment time-point, with only one in each sample. While there is, therefore, little evidence to compare between samples, the key unmet needs reported in each study did differ from the other. In the haematology only sample, fear of recurrence was the primary unmet need while in the mixed sample, fear and anxiety were raised. While the needs are different in precisely how they were assessed and reported, we can identify some similarities in that fear is common to both patient groups indicating the presence of psychological need across both.

The final time-point investigated was survivorship. As with the diagnosis time-point, we are unable to form comparisons between patient groups as no studies were identified with a mixed cancer sample at this time-point. In the haematology only sample, a need for information regarding fertility in younger patients was highlighted yet it is not known whether this trend would be reflected in the mixed sample.

How reliable are the stated findings?

Overall, the evidence included within this review was generally of a good methodological standard as determined by the quality assessment which lends credence to the findings. When considering unmet needs that might be most relevant at different time-points, it must be noted that some time-points have less supporting evidence than others. At the survivorship time-point for example, there were no studies identified with a mixed cancer sample and only one conducted with a haematology only sample within which the haematology only group received a comparatively low quality assessment score of 68.2%. This is indicative of a need for further research in this area. Similarly, there were no studies found that assessed need at the time of diagnosis with a haematology only sample and only two that assessed need at diagnosis with mixed cancer samples, again indicative of a lack of research in this area.

When considering the unmet psychosocial needs identified in the three studies that were carried out with participants with haematological cancer only, two of the three studies identified concerns about the cancer coming back, or fear of recurrence, as a key unmet psychosocial need. The third study which did not share the same finding scored a much lower score on the quality assessment, 68.2%, as a result of poor definition of both the needs assessment measure used within the study and of the results more generally. This perhaps suggests that we can have more confidence in the findings predicted by the two studies that highlighted fear of recurrence which obtained quality assessment scores of 100% and 95.4%.

Overall, the highest study quality is found in the studies that assess unmet needs at mixed time-points. The overall lowest quality assessment score was given to a study that falls within the treatment time-point, however, as this study is one of six that assess unmet need at this time-point, the overall quality of the results for that section is buoyed by the higher quality ratings of the other studies.

Discussion

The systematic review into unmet psychosocial needs of haematological cancer patients outlines the scarcity of research in this area. Only 18 papers were identified which had aimed to investigate the unmet needs of cancer patients including those with a diagnosis of haematological cancer, although only three of these placed a specific emphasis on haematological cancer.

Summary of Evidence

The findings indicate the presence of unmet psychosocial needs in haematological cancer patients. Fear of recurrence was the single most commonly identified need, being highlighted in five separate studies, suggesting a real relevance to the patient group. Fear of recurrence, which can be categorised within the domain of psychological need, was highlighted by studies in both the mixed and haematology only samples indicating a more widespread significance across cancers. Indeed, it may be that even fear of recurrence is even more prevalent than suggested (Llewellyn et al., 2008). The study conducted by Liang and colleagues (1990) simply tested for the presence of psychological need in general rather than looking at any more specific needs within this domain and Boyes et al. (2006) reported their results as needs within the psychological domain, psychological being the domain under which fear of recurrence is categorised.

When considering the prevalence and the importance of psychological needs as an overall domain, it is worth noting that the PNI does not include psychological needs as a separate area of need within its subscale structure in the way that alternative needs assessment tools do. There is a category for unmet emotional and spiritual needs which is the closest alternative to psychological needs, but the way in which this type of need is assessed does differ when the PNI is used. The PNI is the method of assessing need in five of the included papers and therefore may have impacted upon the prevalence of psychological needs identified within this review by underestimating the presence of psychological need. Regardless, the results of this review highlight the importance of both fear of recurrence as an unmet need, and psychological needs more generally as an area of importance to those with a haematological malignancy.

The importance of psychological needs has been reflected in the wider cancer literature. A systematic review on unmet needs within a general cancer population found psychological needs to be the second most commonly reported unmet need (12-85%) (Harrison, et al., 2009). This review highlighted the variability of level of need within a general cancer

sample, yet it was difficult to tease apart differences in level of need according to diagnosis. The significant difference in levels of need reported from different studies does raise the suggestion that people with different diagnoses and therefore who experience cancer within different context may experience different needs, explaining this variability. Fear of recurrence as a concern for those with a diagnosis of cancer has been raised repeatedly within the general cancer literature. Two seminal papers within needs research (Bonevski et al., 2000; Sanson-Fisher et al., 2000) found fear of recurrence within the domain of psychological needs to be highly relevant within their samples. Neither of the samples used in these papers however, included patients with a haematological diagnosis which suggests that, in this, haematology and other cancer diagnoses share a common fear. A study published after this systematic review was conducted found that help with worries about spread of cancer or recurrence was amongst the least well met needs (Morrison et al., 2012), although interestingly this wasn't the case within the haematology participants. Whether this was because this need was not felt to be relevant to participants or because this need was felt to be met amongst the haematology patients is unclear, although fear of recurrence was not rated within the top five least salient needs by the haematology patients indicating some recognition of importance.

Information needs were identified within five separate studies, as was fear of recurrence, however the way in which unmet information needs were identified differed between these studies and the precise need identified by participants was not the same throughout. For example, the haematology only study carried out by Hammond and colleagues (2008) highlighted an unmet need for information relating to fertility for younger patients whilst in the work by Mesters et al. (2001) unmet needs for information about disease and treatment were identified. As an overall area of need therefore, information needs emerged strongly but there is less continuity between studies. The reason for this may lie in the way in which needs were assessed by different studies, for example the previously mentioned study by Hammond (2008) focussed specifically on the assessment of unmet needs relating to fertility in patients with NHL and therefore it is not surprising that this is what their findings highlighted. We do not know from the data available whether, had this study assessed for information needs more generally, a more homogenous pattern of unmet needs would have emerged. The wider literature relating to information needs suggests that needs of this nature are often rated highly by patients as being important to them (Bonevski, et al., 2000; Meredith et al., 1996; Mistry, Wilson, Priestman, Damery, & Haque, 2010; Sanson-Fisher, et al., 2000). For cancer patients, the source of their

information most often comes from the healthcare professionals involved in their care and a previous systematic review focussed on information needs within a general cancer population found that information needs related to treatment are the most frequent (Rutten, Arora, Bakos, Aziz, & Rowland, 2005).

Concerns about the worries of those close to you emerged as being important at the treatment time-point in studies conducted with mixed cancer samples. While this was not highlighted as one of the most prevalent unmet needs within a haematology only sample at diagnosis (Molassiotis et al., 2011), four unmet needs relating to a patient's significant others appear in the 15 most commonly identified unmet needs. This suggests the potential for needs relating to patient's loved ones to be key to both samples, however, with limited research published in haematology samples, it is not possible to form any firm conclusions. This need is not one that has been highlighted by previous systematic reviews on general cancer samples, and, even within this review it does not appear as a homogenous need. As previously discussed, the variations in needs assessment tools may in part explain the absence of this need in previous works, however, it is also possible that concerns about those close to you is a psychosocial need with a specific relevance to haematological cancer patients.

Needs relating to fertility were raised in studies conducted by both Hawkins et al. (2008) and Hammond et al. (2008) meaning that it was raised across both haematology and mixed samples. There were differences in exact unmet need identified, although the general theme of fertility was shared. As with other areas of unmet needs, the presence or absence of unmet needs relating to fertility could be attributed to the way in which the assessment tool used within the studies categorised need. The focus of some papers may have excluded fertility issues from being identified because of choice of measurement tool used, and so this would need further investigation before any firm conclusions could be made. As with concerns about those close to you, needs relating to fertility have not been raised as important in previous reviews of need. Again, this could be related to the way in which types of unmet needs are assessed for, however, it could also indicate a need that is specific to this patient group.

Overall quality and robustness of results

The majority of the included studies scored well in the quality assessment. The lowest quality score achieved was 54.5% while 13 of the studies scored over 80%. The decision to only review published literature had a positive impact on the quality of the research

included within the review as all papers have been through a peer assessment process and were found to be of an acceptable standard prior to publication. Common reasons for studies scoring lower on the quality assessment were small sample sizes, poor response rates and a lack of detailed reporting of the work. Within the wider psycho-oncology literature, response rates are a key issue. The innately small sample size of some of some cancer populations can also be problematic, an issue that is discussed at greater length in Chapter 6 of this thesis.

There were differences in the way in which studies were designed and carried out that limit how easily trends within the data can be determined. Within the data collated from the longitudinal studies of mixed cancer patients, the level of unmet psychosocial needs was found to decrease over time. Due to the lack of longitudinal data within the haematology only sample, it is not possible to develop comparisons and it is therefore uncertain to what extent this trend is relevant in haematology.

A methodological weakness of the included papers as a group was that only three studies were found that looked solely at haematological cancer patients. There were no studies identified in either sample group that looked at needs in haematological patients at the survivorship phase, meaning that there is no research evidence looking at long term unmet needs in these patients. There are some similarities when studies are grouped according to diagnosis and time-point, however, no single group contains more than six studies. These relatively small sample sizes mean that generalisability of the results drawn from these groups is limited and that exploration of sub-sample differences was not possible.

Consequences of Unmet Psychosocial Needs

The impact of the presence of high levels of unmet needs lies at the heart of needs research. It is thought that high levels of unmet needs are associated with the presence of psychological distress (McIllmurray et al., 2001), however, this association has been poorly tested. Of the three studies included in this systematic review that focussed solely on haematological diagnoses, only one required participants to also complete outcome measures along with the measure of unmet needs. The study conducted by Molassiotis and colleagues (2011) included the Hospital Anxiety and Depression Scale (HADS) and the EORTC QLQ-C30 and the myeloma specific MY20 and found that both anxiety and depression were prevalent within their sample. This study found a relationship between the 'side effects of treatment' subscale on the EORTC MY20 and level of unmet needs. However, this study was looking at predictors of unmet needs, not at the impact that

unmet needs have upon psychological wellbeing. The fact that a relationship was found between a quality of life subscale and unmet needs indicates that there is the potential for a predictive relationship between needs and outcomes. At present however, there is too little research conducted within this specific patient group to cast any firm judgement as to the reliability of any such relationship.

More work is needed that evaluates the levels of unmet psychosocial needs in haematological cancer patients over longer periods of time. Ideally future work would also include common psychological outcome measures such as anxiety, depression, quality of life, adjustment and coping to investigate the possibility of a causal relationship. This work would allow us to feel confident in our knowledge and understanding of unmet need and would feed into the current culture within healthcare services towards risk stratification (Watson et al., 2012). At the present time, and on the basis of the evidence identified, we are not in this position and more research is required. If the factors involved in causing psychological distress were better understood then more support could be provided to those at risk at an earlier stage to minimise the presence of distress in patients.

For the purposes of this review, outcomes can be defined as the presence of unmet needs. The results of the review highlighted variations in the type of unmet needs identified, which can potentially be attributed to differences between the ways in which unmet needs were assessed. Of the 19 papers included within the review, there were 11 different needs assessment tools used. Different assessment tools mean differences in the ways in which needs are classified which will impact upon the types of needs identified. Even where needs appear to fall within the same category differences in categorisation limit generalisability, for example psychological needs were identified as was fear of recurrence. Within research, fear of recurrence is often classed as a psychological need, however, when a paper uses an assessment tool that simply asks participants whether they have any psychological needs, it is unclear what exactly this means to participants when they chose to acknowledge this need. Additionally, some papers chose to focus their investigations upon a specific aspect of psychosocial need, for example information needs, meaning that this was the only category of need identified within that paper. This has led to some needs being commonly identified within this review but it is unclear whether they would have the same prominence had all studies assessed needs in a common manner.

Conclusion

In conclusion, this systematic review identified 18 relevant papers via systematic searches of relevant databases and journals in addition to examining the reference lists of included papers. Each paper in some way assessed unmet psychosocial needs in a quantitative manner in an adult sample that included participants with a diagnosis of haematological cancer. Prevalence of unmet psychosocial needs, type of psychosocial needs identified and the trends within the data were found to be highly variable with very limited data available in some of the areas investigated. The key unmet psychosocial needs most relevant to this patient group appear to be fear of recurrence, psychological needs and information needs. However, these conclusions are likely to be, at least in part, due to the way in which the current evidence base has attempted to identify unmet psychosocial needs in this patient group. In addition, few studies attempted to look at the trajectory of the levels of unmet psychosocial needs over time meaning that there is currently a lack of information regarding how haematological cancer patients' needs may change over time.

While this review may have succeeded in providing an indication of where potential key needs may lie, it is not yet possible to draw any firm conclusions with regards to the type and prevalence of the unmet psychosocial needs that play the biggest role in the psychological wellbeing of this patient group. This review highlights the need for further research that assesses unmet psychosocial needs in haematological cancer patients, in particular via longitudinal cohort studies that assess type and level of unmet psychosocial need over time. The current evidence base is on longitudinal trends in needs is also lacking, no such studies were identified with a haematology sample. Moving forwards, there are two key concerns: 1) standardisation of assessment for greater consistency; and, 2) the systematic identification of need in clinical practice. This systematic review sought to understand type and prevalence of unmet need; as such, qualitative studies were not included within the review. The lack of evidence found during the review process however, highlights the potential utility of qualitative research to act as preparatory work for future quantitative studies and that will expand our understanding of need to include why areas of need are felt to be relevant or important to patients. As such, the work explored in the next chapter (Chapter 3), will seek to build on this and to introduce the patient voice into this body of work before moving on to quantitative identification of need in Chapters 4 and 5.

Chapter 3 - The Lived Experiences of Patients with Non-Hodgkin's Lymphoma: An Interpretative Phenomenological Analysis

Overview

The systematic literature review of the unmet psychosocial needs of haematological cancer patients (Chapter 2) outlines a scarcity of research. Without having an appreciation of the type of needs that are important to patients, and truly understanding the causes and implications of unmet needs, it becomes difficult to create a standard of evidence-based practice within our healthcare service. The present chapter will outline the development and findings of a qualitative study that aimed to: identify the unmet needs of haematological cancer patients; to understand how well suited existing needs assessment tools are for this patient group; and to understand the patient experience of living with this diagnosis and the impact of unmet need. By understanding both how unmet need is currently assessed in cancer patients, and what this specific patient group perceive as being important, as researchers and clinicians we will be better placed to understand optimal ways of assessing need and to act on those needs. The lack of existing literature that examines type and importance of unmet needs in this patient group means that, at present, the patient's voice is absent from the research literature.

Background

The assessment of psychosocial needs in oncology, while generally recognised as having merit, is currently unsystematic at best and often neglected altogether. Over recent years, there has been an emphasis on improving patient assessment following the publication by the National Institute for Clinical Excellence (NICE), Guidance for Improving Supportive and Palliative Care for Adults with Cancer (2004). This highlighted the importance of considering the patient experience of receiving a diagnosis and treatment for cancer. A previous study that examined the extent to which GP practices in the UK have adopted recommended practices for supportive and palliative care found adoption to be highly variable (Hughes, Bath, Ahmed & Noble, 2010).

The need for psychosocial assessment of cancer patients becomes clear when we consider the estimated prevalence of distress in haematology patients as being as high as 50% for some diagnoses (Zabora et al., 2001). Allowing distress to develop not only goes against the best interests of the patient, but is also likely to prove more costly for health services in the longer term (Carlson & Bultz, 2004) as greater levels of psychological input are required. Early intervention for mental health problems is widely recognised as being beneficial for the maintenance of psychological wellbeing (Antoni et al., 2001), yet screening for the presence of distress is not practiced routinely within cancer care (Jacobsen, 2007).

Carrying out needs assessments in people who are living with a diagnosis of cancer can highlight areas in which that person is experiencing difficulties. Needs relating to psychological wellbeing, social support, practical issues or communication with others have all been highlighted as being present in cancer patients (Sanson-Fisher et al., 2001; Harrison et al., 2009) and, if left unaddressed, have the potential to cause considerable psychological distress. Assessing for unmet needs could highlight potential problems before they occur, and at the very least make clear to those providing care to the patient where extra support is required.

Psychosocial need is an area that has also received increased attention from the academic psychosocial oncology community over recent years, the focus predominantly falling on descriptive studies aiming to document the specific psychosocial needs that are most relevant to a particular patient group. The assessment of psychosocial needs differs from the assessment of distress in that the focus of the needs assessment is to determine where patients feel that they require assistance with their concerns, rather than simply acknowledging that there is a concern but finding that the patient has no desire to address this with their clinical team, perhaps wishing to seek support elsewhere (Carlson, Waller & Mitchell, 2012).

As discussed in Chapter 2, while there has been an expansion of work investigating need within cancer patients in general, there has been little that has done so specifically in patients with haematological malignancies; the specific requirements of this patient group thus remain largely unknown and unexplored. The systematic review identified just three papers that assessed need in haematology patients only and, of these papers, only one assessed need across the whole spectrum of diagnoses. The review indicated some

similarities in the type of needs found in both haematology and solid tumour cancer groups, however, there are also indications that there may be key differences.

What are the differences in need between haematological and other cancers?

There are recognised differences between cancer patients with a haematological diagnosis and a diagnosis of a solid tumour (NICE, 2004). Haematological malignancies are different in the way that they present, are treated and in their likely prognosis when compared with other cancer types (NICE, 2004). The much publicised scenario where a patient finds a lump and seeks medical advice does not apply to those being diagnosed with a haematological cancer. More common are symptoms of tiredness, weight loss, fever, breathlessness or night sweats. These are not the typical symptoms generally expected of cancer, as such, a new patient may not present to their GP with the expectation of a cancer diagnosis. Indeed, some report delayed diagnosis due to the fact that their symptoms are confused with other, less troublesome, diagnoses (Caplan, 1996).

Treatment options for those diagnosed with a haematological malignancy are notably intensive in nature. Bone marrow transplants can be used to treat both acute and chronic leukaemia, along with myelomas in certain circumstances. A bone marrow transplant involves the harvest of healthy bone marrow stem cells from the donor and transplanting them into the bone marrow of the recipient (CRUK, 2013). The risk of infection is greatly increased, and, the recipient is often placed in protective isolation. This, combined with the fact that the patient will feel very unwell for an extended period of time makes this a distressing time for patients, with a number of studies highlighting a link between bone marrow transplant and post-traumatic stress disorder (Jacobsen et al, 1998; Johnson Vickberg et al; 2001). At the other end of the treatment spectrum, some patients will receive no treatment at all in the months, or even years after their diagnosis. 'Watch and wait' is a term used for the monitoring of patients who have received a diagnosis of haematological cancer but who do not yet require immediate treatment. Instead they will often attend via an outpatient clinic for regular blood tests to monitor any progression of their disease (Leukaemia and Lymphoma Research, 2011). This can present a psychological challenge for patients, albeit in a different way to the difficulties associated with of bone marrow transplantation. Not receiving treatment after being given a cancer diagnosis may feel counter-intuitive to patients and is often not in line with their preconceptions about what it means to have cancer. While treatment can be physically and psychologically difficult, it can also instil a sense of hope and of moving forward towards regaining a sense

of normality. Conversely, the lack of treatment can mean that patients feel a lack of progress and like they are waiting indefinitely for something to happen.

In addition to the differences in the way haematological cancers can be treated, the settings in which they are treated can also differ. Previous research has highlighted that people with a haematological cancer are significantly less likely to be treated in a palliative care or hospice setting than those with other cancers (Howell et al, 2011). Potential reasons for this are continued care provision from the haematology team, an uncertainty around when it is appropriate to refer someone into palliative care and a quick disease trajectory meaning that there is little time in which the patient can receive palliative care. The bulk of this research is comprised of qualitative research carried out in Australia (McGrath, 2001; McGrath, 2002; McGrath & Holewa, 2006). It is not clear whether patients in the UK experience similar unmet care needs. NICE (2003) recommend the integration of haematology and palliative care services from the point of diagnosis however, if the scenario that patients remain under the care of the haematology team is accurate, it may be that any needs are met by that team, making the lack of a transition to palliative care services one that concerns the correct implementation of policy rather than a cause of concern or unmet needs for patients.

These differences between haematological cancers and solid tumours give rise to the possibility that the type of unmet needs associated with the two groups of diseases may differ. Haematological cancers begin with different symptoms, may be diagnosed differently, treated differently and have care provided by different services. Findings from the systematic review demonstrate that psychological needs feature highly in those with haematological cancers, something that may be tied into these differences and the surrounding sense of uncertainty, however, this knowledge comes from a very limited evidence base. We also know from previous research that treatment for haematological cancer can affect a person's ability to fulfil their usual roles in society: social, vocational and relationship roles can all suffer (Sherman et al., 2005). When looked at in combination with the high distress rates in haematological patients (Carlson et al., 2004), a strong rationale emerges for the further exploration of the type of unmet needs present in haematology patients and to qualitatively explore their experiences of cancer and how this feeds into the type of need experienced.

Assessment of Unmet Psychosocial Need

Current needs assessment tools

As the amount of literature describing trends in unmet psychosocial needs in cancer populations has grown, so too have the number of needs assessment tools that are available for clinicians to use. Existing needs assessment tools can be broadly characterised according to the time-point at which they were designed to assess patients' level of unmet needs, however, the majority of measures have been designed for use in patients with any type of cancer diagnosis (Carlson, Waller & Mitchell, 2012). A small number of measures have been developed for use within specific diagnostic populations, namely lung cancer (NA-ALCP), prostate cancer (PCNQ) with others developed for specific groups such as advanced cancer patients (NA-ACP, NEST, SPARC-45). There is a tool that was developed for both lymphoma and colon cancer patients that assesses concerns relating to their treatment (CaTS – Schofield et al., 2012). However as this measure states that it is to be used to measure patient concerns in the lead up to the start of chemotherapy, it falls outside of the definition of a needs assessment tool (see Chapter 2). More recently, the Supportive Unmet Needs Survey (SUNS), a needs assessment tool developed for use with cancer survivors (Campbell et al., 2010) has been assessed for both validity and reliability when used with haematological cancer survivors (Hall et al., 2014). This study has begun to address the gap in the literature regarding appropriate use of measures in haematological cancer samples yet predictive validity, test-retest reliability and confirmation of the factor structure still need to be confirmed.

The distinction between measures that assess need and those that assess concerns is not always clear or easily distinguished within the literature. Often those measures that are used to assess patient concerns are grouped together with those that measure needs (Carlson et al., 2012). As needs are being defined as something that is required to underlie a person's emotional and psychological wellbeing, then the fact that a patient has a concern within this area does not necessarily equate to them wanting further support from the hospital to meet this need (Baker-Glenn et al., 2011). For example, it has been shown that even those who present with clinically significant levels of distress do not necessarily want support from their treating hospitals to manage this (Baker-Glenn et al., 2011; Mitchell et al., 2011). A recent systematic review aimed to collate all of the current tools that assess unmet need specifically in cancer patient (Carlson et al., 2012). The majority of the assessments found were created to be able to assess need in patients with any type of cancer diagnosis with a smaller subset designed to assess the specific needs of those with

advanced disease, within a specific clinical setting or of cancer survivors. In total, 29 assessment tools were identified that were deemed to assess unmet needs in cancer patients. Further examination of the literature suggests three that are most commonly employed within research studies:

- The Cancer Survivor's Unmet Needs measure (CaSUN) was designed as a self-report measure to assess cancer survivor's supportive care needs (Hodgkinson et al., 2007). It includes questions about the patient's information and medical care issues, quality of life, emotional and relationship issues and the impact that cancer has had on life perspective ranging from no need/not applicable to high need. The measure was developed based on an examination of existing literature, needs assessment tools and a prior qualitative study of unmet needs with cancer survivors and their partners.
- The Supportive Care Needs Survey (SCNS) was originally developed to assess the unmet needs of cancer patients undergoing treatment (Bonevski et al., 2000; Sanson-Fisher et al., 2000). The measure assessed needs across a range of areas: psychological, health system and information, physical and daily living, patient care and support and sexuality. The original SCNS has been developed into a smaller version, the SCNS SF-34, with the aim to make the assessment less burdensome and, therefore, more likely to be used regularly in a clinical setting (Boyes et al., 2009).
- The Needs Evaluation Questionnaire (NEQ) was designed to assess the informative, psychological, social and practical needs of hospitalised cancer patients (Bonevski et al., 2000). The measure was created based upon interviews with patients regarding their psychosocial needs.

The assessment process

As part of their Guidance on Improving Supportive and Palliative Care for Adults with Cancer (NICE, 2004), NICE spearheaded a new drive for the assessment of patient need in cancer. This guidance recognised the need to assess patient need and the fact that needs were not always met. Patients being unaware of the services available, healthcare professionals being unaware of the benefits of referring patients to supportive services, professionals not eliciting the needs of patients during consultations and poor communication between healthcare professionals were all cited within the report as barriers to implementation. Since 2000, there has been an increase in the amount of

research published relating to the unmet needs of cancer patients, indicating an increasing awareness of the needs to address this issue in order to improve patient outcomes.

A report on patient need also published in 2004 (Richardson et al, 2004) found that over half of needs assessments conducted in a clinical setting were carried out by nursing staff with over three-quarters of assessments taking place face-to-face between patient and healthcare professional. Perhaps most pertinently, the average time taken for an assessment was 38 minutes. In an environment where time is often precious and the average consultation time is short (Howie et al., 1999), this raises issues for the feasibility of conducting regular needs assessment for all patients in the secondary care setting.

How often a needs assessment is, and should be, carried out in the clinical setting remains a pertinent issue. The National Cancer Patient Survey in 2011/2012 found that only 24% of cancer patients were offered a needs assessment and subsequent care plan (NCIN, 2012) while research has indicated that 30% of patients are left with unmet needs after the completion of treatment (Armes et al., 2009). The National Cancer Action Team (NCAT) suggests that needs assessment should take place at a range of key time points from diagnosis onwards as standard (NCAT, 2013). The average time taken to complete a needs assessment, with further time required to put together, implement and continually monitor a comprehensive care plan, may go some way to explain why this process is still absent for the majority of cancer patients in the UK. It is also unclear to what extent this process is valued by patient, something to be addressed by qualitative research. While previous research has indicated that unmet needs are common in cancer patients (Harrison et al., 2009), there has been little research conducted into whether or not patients feel that needs assessment is an important part of their overall care and to what extent any resulting care plans are valued. These statistics relate to the degree of needs assessment that takes place within a general cancer setting, there is even less research available that indicates to what extent haematology patients are routinely offered these resources. What is clear is the need for a holistic assessment of patient need in order to be able to understand which needs are most important to patients and which needs should be addressed by the care team.

Who were current needs assessment tools designed for?

In general, needs assessment tools are developed to assess the needs of a specific patient group and are developed and validated accordingly. Some tools have been developed for the assessment of needs at a specific time point with measures developed for patients with

active disease (Tamburini et al., 2000), for survivors (Hodgkinson et al., 2007) and patients in palliative care or at end of life (Osse et al., 2004). Most tools however, were developed for generic use with cancer patients and for use within an outpatient clinic.

In theory, a needs assessment using a specific tool should, therefore, only be carried out at the time point for which that measure was developed. The extent to which this happens is practice is unclear. We know that needs assessment is often unsystematic (Carlson et al., 2004), with levels of implementation varying between clinics and even between clinicians. It is likely that each clinic has one specific measure that they adopt to assess their patients regardless of timing or other clinical factors. In addition, while all of the tools identified were developed with the aim of assessing unmet need, the precise focus of the assessment can vary. Not all tools will assess unmet needs across all domains and not all tools assess the extent to which a patient desires help or assistance with their unmet need (Richardson et al., 2007). The generic needs assessment tools, therefore, have the widest clinical utility and are perhaps more likely to be adopted at practice level.

The practicality of an assessment tool is a key concern when considering how best to make assessment an integral part of practice. Time taken to complete the tool can vary considerably, with estimates between five minutes and 45 minutes for different measures (Richardson et al., 2007). The method of implementation also requires consideration: most commonly, assessment tools are self-completion measures that patients can complete with minimal input from the clinical team (Bonevski et al., 2000; Sanson-Fisher et al., 2000). Other measures require an interview with the clinical team (First & Gibbon, 2004). There are benefits to both approaches, with an interview with a healthcare professional allowing for a more in-depth exploration of the person's need and the healthcare professional can provide the meeting of their needs. This approach, however, is more time intensive for clinicians and may make this approach unfeasible for large numbers of patients, a particular problem within outpatient clinics.

Why do we need to understand patient's perceptions of need rather than just be able to identify them?

Previous research on unmet needs in cancer has comprised of quantitative studies that use an assessment tool to determine whether or not a person has an unmet need in a specific area. This is valuable information and well-suited for a quick assessment within the clinical setting, but is limited in how much it can tell us about why people are rating needs as unmet. In some cases, it may be that a person indicates that they have many unmet needs

but that, on further investigation, each of those unmet needs is only impacting upon the person's life in a small way. Conversely, someone may only rate a small number of needs as being unmet but that does not mean that those unmet needs are not causing a significant level of distress or impairment.

A more recent needs assessment tool (Morrison et al., 2012) went some way to address this by indicating not only the presence of need but also saliency of that need and the degree to which these needs have been met. Prior to this, few tools had addressed both issues. Many needs assessment tools will include a 'not applicable' option for patients who don't believe that the need in question applies to them, but this style of quantitative assessment cannot tell us why that patient does not feel that a specific need is not applicable. It may be that the patient is genuinely unaffected by the issue or, it might be that they do not wish to address that specific concern with their healthcare team. Qualitative research allows researchers to explore the patient experience and the meanings behind the tick box. This can indicate not just what needs are present but why they are important to patients and the extent to which an unmet needs impacts upon a person's wellbeing. This study attempts to fill the literature gap with relation to understanding the context of unmet need for haematological cancer patients.

What were the aims of the study?

This study aimed to answer Thesis Question 2:

> ***What do haematological cancer patients perceive to be their key areas of psychosocial need and why were those specific needs important during the patient experience of cancer?***

Secondary objectives included: (a) forming a deeper understanding of why specific needs are important and relevant to patients; and, (b) to use the data gathered to assess how suitable current needs assessment tools are for assessment within this patient group.

Methodology

Design

This study involved two phases. A thematic analysis of existing needs assessment tools was undertaken to determine type of need identified across published measures. This was followed by a series of focus groups that investigated patient views on the type and level of psychosocial need present within those diagnosed with a haematological cancer. Each focus group involved an unprompted discussion of needs and experiences, followed by a more structured discussion of areas of need based upon the areas highlighted within the thematic analysis. The original intention was to run a series of focus groups organised according to diagnosis: one with patients diagnosed with an acute leukaemia or a high grade lymphoma; one for patients diagnosed with chronic leukaemia or a low grade lymphoma; one for patients diagnosed with myeloma; and one for healthcare professionals working within a haematology oncology setting. The rationale for organising the groups this way was to run focus groups with participants who had all experienced similarities in both the type of diagnosis received and the likely treatment undertaken. Due to lower recruitment rates than expected, three focus groups ran, all with patients with a diagnosis of Non-Hodgkin's Lymphoma. Reasons for this will be explored later in the chapter.

An Interpretative Phenomenological Analysis approach was adopted for analysis of this data which was especially suited given that one of the primary goals of the study was to understand lived experiences of need within this patient group (Smith, 2004). IPA allows the researcher to develop a deeper understanding of the phenomenon in question than other qualitative methodologies by seeking to not only reduce the phenomenon to a discrete set of categories, but by studying the phenomenon within the context in which it is experienced by those with first-hand experience (Giorgi & Giorgi, 2008). This was necessary, along with the quantitative studies later in this thesis, in order to fill the current gap in the literature and to inform effective interventions to meet the needs of this group.

Participants

The initial recruitment strategy for this study was to recruit patients with a variety of haematological diagnoses and to run a series of focus groups with participants grouped according to their diagnosis. In the four months that recruitment was open for the study however, only participants with a diagnosis of Non-Hodgkin's lymphoma had been identified and consented.

In total, six participants were recruited into the study and together made up a homogenous sample group. All had been diagnosed with Non-Hodgkin's lymphoma, all were white British, all had been treated at the same hospital, all were within a similar age range, lived within a similar geographic area in the North West of England, had partners, and were working at the time of diagnosis. There were five males and one female in the sample.

Sample Size

Sample size in qualitative research can be a divisive issue, with fewer 'rules' in place than for quantitative sample size calculations. When making a decision regarding sample size in qualitative research, the epistemological, methodological and practical issues must be taken into consideration (Baker & Edwards, 2012). The epistemological position here takes a phenomenological stance, yet the interpretive nature of IPA as a methodology must also be considered. IPA typically utilises small samples, most often between three and 15 (Brocki & Wearden, 2006), although between three and six has been cited as the optimal sample for student theses (Smith, Flowers & Larkin, 2009). This is much smaller than would be deemed appropriate for other qualitative methodologies, where 50 has been proposed as an appropriate number of participants for a PhD thesis (Baker & Edwards, 2012). IPA is concerned with detail, with understanding the complexity of human thoughts and emotions, as such it is believed that keeping the sample size small creates the optimum balance of quality over quantity. A 'concentrated focus on a small number of cases' should allow for the development of areas of both similarity and of difference between participants, yet prevent the researcher from becoming overwhelmed by the amount of data and the level of analysis required by IPA (Smith, Flowers & Larkin, 2009).

When considering the demands of IPA as a methodology, and taking into account the research communities' prior experience with sample size for this methodology, it was felt that 6 was a sufficient number of participants from which a solid IPA could be developed. In addition, this was appropriate for the practical constraints that are present when conducting research with cancer patients, the recruitment strategy is outlined below.

Recruitment

Recruitment of patients took place in collaboration with the clinical staff team at the Countess of Chester Hospital Haematology Oncology ward under the guidance of the Consultant Haematologist. The clinical team identified patients meeting eligibility criteria for the study and provided a brief introduction regarding the premise of the study and what taking part would involve. In addition to a verbal introduction to the project,

potential participants were provided with a flyer (Appendix 8) and a consent form (Appendix 9) to indicate whether or not they were interested in receiving more information from the research team. The inclusion criteria for each focus group were as follows:

- Adult over the age of 18.
- A diagnosis of haematological cancer.
- Not currently undergoing active treatment.
- Able to provide informed consent.
- Currently a patient at the Countess of Chester Hospital.

If a patient indicated that they wished to receive more information, a full information pack was posted out to them containing an invitation letter (Appendix 10), an information sheet (Appendix 11), a demographic questionnaire (Appendix 12) and a consent form to be filled in should the patient wish to take part in the study, along with a pre-paid envelope addressed to myself at the university in which the consent form could be returned.

As previously highlighted, though patients with all haematological cancer diagnoses were eligible to take part in the study, only patients with NHL were successfully recruited. There are several possible explanations as to why NHL was the only diagnosis recruited within the timeframe:

- Overestimation of the numbers of patients who are no longer receiving active treatment but that are still attending regular clinic appointments. (NHL is the most commonly diagnosed haematological cancer and therefore, as a patient group are more commonly seen on a regular basis within the clinic setting.)

- Acute leukaemia were less likely to meet the inclusion criteria as they are more likely to be undergoing treatment, do not survive to the survivorship stage required, or are “cured” so do not come into clinic on a frequent enough basis to be picked up within a few months’ timeframe.

- Comparatively lower incidence of myeloma in comparison with NHL patients. Myeloma is additionally an incurable diagnosis and, as such, there are few who have completed treatment/are not receiving active treatment for their diagnosis.

After a four month recruitment period, the decision was made to cease recruitment and to move forward with the study with a sample that was smaller in size and clinical scope than initially anticipated. Considerable challenges encountered when attempting to recruit

participants into the study. While homogeneity within the sample was appropriate given the use of IPA, it does reflect a wider problem within psychosocial oncology research in attempting to recruit diverse samples that reflect society within the UK today. However, the dominance of males within the sample was deemed positive as men are typically harder to engage in psychosocial oncology research than women. Indeed, difficulty recruiting cancer patients into psychosocial studies is a challenge beyond that presented within this thesis and is a challenge for psychosocial research in the UK today, the causes and implications of this are discussed at length in Chapter 6.

Of those recruited, saturation appeared to be achieved with some patients approached twice (over consecutive clinic visits) by the healthcare team. As this study was intended as a preparatory study to later empirical work, it was felt that allowing the recruitment window to continue for an unlimited period of time was neither feasible nor helpful to the thesis aims. Additionally, an IPA approach was already intended: this is idiographic in nature and therefore small, homogeneous samples are common and to be expected. The number recruited was sufficient for this analysis to be performed in line with published methodological guidance (Smith & Osbourn, 2004; Brocki & Wearden, 2006).

The Development of a Focus Group Schedule

Prior to conducting the focus groups, a thematic analysis of existing needs assessment tools was carried out in order to create a list of psychosocial needs that were currently recognised by existing measurement tools. There were several reasons for doing this: i) to create a prompt for discussion during the focus groups; ii) to facilitate a discussion regarding whether the needs identified were deemed important or relevant by haematology patients; and, iii) to determine to whether the needs of haematology patients were included in these measures developed for general cancer samples and, therefore, whether or not current tools were adequate for the assessment of unmet needs in this patient group.

A separate literature search was conducted in addition to the systematic review outlined in Chapter 2 in order to identify existing needs assessment tools. PsychINFO, Medline, Cinahl and Web of Knowledge were searched along with Google Scholar. To be included, tools had to assess unmet needs and be specific about this as their purpose. Tools that assessed concerns, problems, or other psychosocial outcomes were not included.

In total, 12 needs assessment tools were identified and included within the thematic analysis:

- Patient Needs Assessment Tool (PNAT) (Coyle et al., 1996)
- Needs Near the End of LifeScale (NEST) (Emmanual, Alpert & Emmanual, 2001)
- Problems and Needs in Palliative Care Questionnaire (PNPC) (Osse et al., 2004)
- Needs Evaluation Questionnaire (NEQ) (Tamburini et al., 2001)
- Supportive Care Needs Survey (SCNS-LF59) (Bonevski et al., 2000; Sanson-Fisher et al., 2000)
- Cancer Rehabilitation Evaluation System (CARES) (Ganz et al., 1992)
- Information and Support Needs Questionnaire (ISNQ) (Chalmers et al., 2003)
- Patient Needs Inventory (PNI) (Thomas et al., 2001)
- Oncology Clinic Patient Checklist (OCPC) (Romsaas et al., 1983)
- Sheffield Profile for Referral and Assessment for Care (SPARC) (Ahmedzai et al., 2004)
- Cancer Survivors Unmet Needs (CaSUN) (Hodgkinson et al., 2007)
- Supportive Unmet Needs Survey (SUNS) (Campbell et al., 2010)

Each needs assessment tool was examined and a collated list of the needs assessed in each was created (Appendix 3). The list of questions was then analysed using a thematic analysis approach to group like needs together and to eliminate duplicates. Once this was completed, the resulting list of needs was analysed to identify overarching areas of need that could be grouped together (Appendix 4). The final list of themes was tabulated and then used as a prompt within the focus groups (Appendix 5).

A semi-structured interview schedule was created based upon the findings from the thematic analysis of assessment tools. The schedule retained a large degree of flexibility to include some unprompted discussion of experiences and concerns encountered and therefore the ability to explore in more depth areas of need that were identified as being of importance to participants, although the researcher ensured that each area of the schedule was included within each focus group. To assist in this, after an initial period of unprompted discussion, each participant was provided with a table that included the areas of need identified by the thematic analysis of existing measures (Appendix 3 and 4).

Each focus group ran to the same overall schedule as detailed below:

1. Unprompted discussion of their needs/their understanding of patients' needs.
2. Time to look at the item pool drawn up from existing needs assessment tools and discussion of the relevance of items.

3. The comparative importance of both the needs that they themselves identified and the needs identified from the current assessment tools.
4. Participants were asked to highlight the needs most important to them and to rank them where appropriate.

The interview schedule was intended to be open-ended, utilising the schedule to facilitate discussion and to allow participants to tell their story. All interviews were audio recorded on two tape recorders for transcription purposes. In the case of sound interruption, ambiguity or interference the researcher would leave the interfered section as inaudible.

Procedure

Prior to participant recruitment, ethical approval was obtained from the University of Chester, the NHS Research Ethics Committee, and local research governance approval secured at the appropriate site.

Data was collected using focus group methodology. Focus groups can be an excellent way of encouraging participants to think laterally and to explore ideas that they may not have brought up if interviewed alone. This new thinking about a topic can result in the formation of new ideas and create a much more in-depth discussion than might otherwise occur. Additionally, focus groups can seem like a more comfortable environment for participants, particularly when discussing sensitive or potentially distressing topics as they are with others who have experienced the same phenomena (Halcomb et al., 2007). A group setting can allow for a participant not to take part in a discussion if they feel uncomfortable with a specific topic. Of course, this can also have disadvantages and, when conducting group interviews, the researcher must work harder to ensure that all members of the group seem comfortable with the discussion. Having a co-facilitator is a real benefit when running a focus group as the second person can be on hand to assist any participant who needs any help or support during the session without disrupting the rest of the interview. The role of the facilitator is key to a successful focus group: they must be comfortable in leading the group and have the interpersonal skills required to moderate the session well (Gibbs, 1997).

While focus groups can be beneficial in seeing how participants interact within a group dynamic, for this research study, it was important to maintain the individual accounts of each participant's experience of their illness to allow for an in-depth IPA analysis of each experience to take place. As such, small focus groups were ideal and a maximum of three or four participants was included in each. Due to the timing of each group however, none

of those conducted exceeded two participants. While two participants constitutes a very small focus group, the decision was made to go ahead as it was felt that two participants was enough to generate the benefits of a focus group format already mentioned, while in addition may also be helpful in the context of an IPA study in that it would allow for the individual's narrative to emerge with greater ease.

Each focus group was held at the Countess of Chester Hospital where a seminar room away from the ward environment was made available. It was felt that this would be a more comfortable environment for participants rather than being on the ward where they had been diagnosed and treated for their NHL.

Data analysis

IPA is a qualitative research method that seeks to put the meaning placed upon a phenomenon by the participant at the centre of the analysis and resulting understanding, an approach that has been used widely within health psychology (Brocki & Wearden, 2006). Due to the homogenous nature of the sample and the small sample size recruited, IPA was both ideally suited to the data and research aims by allowing for an in depth exploration of patient experiences, adding a richness to the needs literature and illuminating the importance and relevance of specific needs for this particular patient group.

IPA is concerned with understanding the lived experiences of participants and to understand, in detail, how they make sense of their world (Smith & Osborn, 2008). The method incorporates both phenomenological and hermeneutic approaches in its origins. While other qualitative research methods, thematic analysis included, aim to produce an objective statement regarding an event or occurrence that can be generalised across a population, IPA seeks to understand individual's perceptions and experiences and attempts to examine participant's lived experiences, therefore, adopting a phenomenological stance than other methodologies (Smith et al., 2004). This approach allows the researcher to gain an insight into the participants' inner lives, a factor that was central to the decision to adopt IPA methodology for this study. IPA assumes that participants seek to interpret their experiences in a way that is understandable to them (Brocki & Wearden, 2006) which was appropriate for this study where the primary aim was to provide a depth of understanding regarding why specific areas of unmet need are deemed important to patients during their cancer experiences.

As a philosophy, phenomenology can be traced back to Edmund Husserl in the early twentieth century. IPA is phenomenological in that it seeks to understand how an individual views and understands their world, rather than to try and produce an objective or removed record of an event. Phenomenological research aims to detail a particular phenomenon, to study in depth the first-person experiences of an event or context (Giorgi & Giorgi, 2008). The aim of data collection is to try and capture the lived experience within the context in which the experience took place. From here, analysis attempts to seek the deeper psychological meanings by investigating and seeking to understand these lived examples.

The extent to which the research is able to successfully interpret and make sense of the world as viewed by participants is dependent on their interpretation. IPA involves a two-stage interpretation process (a double-hermeneutic), in that not only must the researcher attempt to understand the participant's world, but the participant must also try to make sense of their own world during the interview process (Smith & Osborn, 2008). In addition, it has been argued that IPA operates a double-hermeneutic in a second way, in how it seeks to form an interpretative position (Smith, Flowers, & Larkin, 2009). IPA can be seen as combining a hermeneutics of empathy, that is to say to attempt to reconstruct the experience within its own context and terms, with a hermeneutics of questioning, to allow the researcher to stand alongside the participant and seek to question and to explore their words. The joint reflections of both participant and researcher come together to form the analytic account of the study (Brocki & Wearden, 2006). It is this combination of empathy and questioning, that creates true understanding (Smith, Flowers & Larkin, 2009).

Traditionally, data collection for IPA has been conducted via semi-structured interviews (Smith & Osborn, 2004), however, the approach has always been used with a degree of eclecticism (Palmer et al., 2010). Indeed, the approach demonstrates flexibility both in its theory and its application. Analysing data gathered from focus groups is a newer application of the method, however, Jonathon Smith, one of the key figures in the development of IPA, endorsed the use of focus group data for IPA as being worthy of further investigation, albeit with a degree of caution exercised (Smith, 2004). Since that time, there have been a number of papers published using both focus groups and IPA (Aubeeluck et al., 2012; Earle et al., 2005), giving an indication of the successful integration of methodology and data collection.

When considering the use of IPA for data collected via focus groups, it is imperative to maintain the ethos of the approach, that the individual narrative of each participant is allowed to be told (Smith, 2004) and the complexity of the interactions within a focus group should not detract from this (Palmer et al., 2010). Each person taking part in the focus group must be given the opportunity to tell their own story in sufficient depth to allow the researcher to understand that individual's experiences. It should be kept in mind that the accounts shared by participants will not only be shaped by the questions asked by the researcher, but also by the shared experiences of all members of the focus group (Palmer et al., 2010).

Homogeneity within the sample, as was the case in the present study, is something commonly associated with IPA (Smith, 2004), and less so with other types of qualitative analysis. Indeed, IPA is concerned with participants' subjective accounts and is not expected to be generalizable to the same degree that a thematic analysis might which seemed to fit with the data and the local knowledge detailed by the participants.

In accordance with IPA recommendations, transcripts were validated independently by a second researcher (Nick Hulbert-Willams (NHW)). Following first analysis by the researcher (BS) NHW selected one transcript (of the three) at random. He read this in full checking both the accuracy of notes made by BS, and adding his own additional thoughts and themes. In addition NHW checked the audit trail of analysis by matching the noted transcripts to the theme tables. Once a first draft of the results narrative was complete, NHW again selected another of the transcripts at random to provide a second level of validation to ensure that the analysis framework proposed fitted with the raw data accurately. In this way, the validation of themes became part of the analysis process as it added a further layer to the exploration and interpretation of the data. Designing research studies in such a way as to maintain a high level of quality and to reduce the potential for bias is essential in the production of high quality studies. Validation is key to this process in qualitative research as it reduces the possibility of misinterpretation of the data and assists in the maintenance of objectivity. Due to the nature of the sample and the use of focus groups, respondent validation was not considered appropriate. As participants were recruited because of their cancer diagnosis, it was felt to be inappropriate to re-contact people whose ongoing health status after the focus group was uncertain. In addition, the decision to conduct the interviews as dyads meant that there

was potential for one participant to comment on another's prose, which was not felt to reflect the true purpose of respondent validation.

Prior to undertaking this piece of research, the researcher had conducted a systematic review of unmet need in cancer patients which provided an a priori assumption that there would be needs present within the sample. This influenced the creation of the interview schedule in that the initial part of each focus group was an unstructured discussion of participant need and experiences with minimal input from the facilitators before moving on the ask participants to comment on pre-existing areas where needs have been recognised in people living with cancer. Having an unprompted discussion at the start of the interview schedule was felt to reduce the chance that the themes generated in the data analysis would be biased by either prior knowledge on the part of the researcher or by the use of the tabulated items resulting from the thematic analysis of existing measurement tools.

Results

Individual's Experiences of Cancer

The initial part of each focus group included an icebreaker question designed to relax the participants and develop rapport. This had the added benefit of allowing more practical background nature about each participant's narrative of diagnosis and treatment. These participant biographies are important as they demonstrate the individualistic nature of how haematological cancer presents and is treated; these are summarised below, including an overview of each participant's reporting of their psychosocial adjustment and experiences.

David

David began his participation in the focus group with a description of his diagnosis process and subsequent treatment. David was unusual in the sample in that he had initially accessed treatment via private healthcare services and this is where the diagnosis was given. David was unhappy with the waiting times cited before he could see a private haematologist and so took it upon himself to find a haematologist who could see him sooner. On the advice of the private haematologist, David moved to be treated in an NHS hospital (on haematologist recommendation) this for treatment due to the experience of staff there in administering chemotherapy. Initially David was monitored on "watch and wait" and found that challenging due to the uncertainty and the expectancy of what was to come. David described the period immediately after diagnosis as the most challenging psychologically and emotionally but then describes feeling able to accept that it was his "turn" to be ill. A strong family support network is described but there are some indications that he did not wish to burden his family with his fears. David was extremely keen to know everything about his diagnosis and treatment, and this is possibly linked to feeling more in control which may act as a coping mechanism. He described some differences in haematological cancers compared to other cancers, likening his lymphoma to a chronic illness. He is very active in his own care, for example speaking at a NICE committee. David also attends a Lymphoma Association support group regularly.

William

William also began his discussion of his experiences with a description of how he was diagnosed and the initial treatment that he received. He described a need to keep positive throughout his experience, both from himself and from those around him. William came across as being very stoical in nature and describes himself as accepting of what has

happened to him. The relationship with the healthcare professionals involved in his care was clearly important to him, perhaps particularly so in light of the fact that he described little in way of a support network although he stated that he has a partner. Physical and practical needs were both endorsed although there was little that was described as having a significant negative impact upon his life.

James

James began his discussion of his experiences of living with haematological cancer with comments on the information that was given at the time of diagnosis. It was felt that clear, simple information was needed here. The initial diagnosis was described as being a shock, but then James seemed to quickly get used to the idea of being ill and began to focus on getting better. James described the presences of unmet support needs within his family, with his wife in particular finding his diagnosis difficult. This concern was on-going, however, as his family did not receive any kind of psychological or practical support. James did have physical needs during his illness but seems to accept these as part of having cancer and was therefore was psychologically able to cope with them. Anxiety only appears to have been present in context of being in hospital and being unclear about what was going to happen to him. Once that immediate anxiety was resolved, the presence of any acute anxiety appears to have diminished.

Mark

Mark was vocal about wanting to know about his illness and treatment and was comfortable addressing this with HCPs. Initially Mark had been very unwell and care had been accessed from multiple hospitals with some confusion over the initial diagnosis. He was very unwilling to identify himself as a cancer patient and actively tried to avoid this by avoiding anything that would tie him to diagnosis. Due to this, body image was a big concern; to him his appearance was a physical manifestation of the illness that he did not want to be defined by. He identified that he had psychological needs and that these were unmet but was very reluctant to engage in any kind of support that might ease these needs. Throughout the focus group, Mark seemed to place locus of control within himself in that he believes needs are met by asking for help and that it is up to the patient to do this.

Ray

Ray began with some discussion of his diagnosis process, describing this as 'fraught' as it was difficult to obtain a precise diagnosis. Initially he is quite descriptive in how he speaks

about his illness, although fairly quickly more emotive language begins to be used. He described significant difficulties coping psychologically once treatment had finished and he no longer had a goal to aim for. Severe anxiety and depression meant that Ray saw a psychiatrist privately when it was too difficult to access psychiatric services through the NHS. He did not go back to work after completing treatment due to the impact of his illness on his mental state at that time. Ray described having a very supportive family but had significant feelings of guilt associated with surviving, with the positive encouragements of others and about living his life after surviving cancer.

Daphne

Daphne was the only female to take part in the focus groups. She described finding it difficult to get a diagnosis initially, after being told by her GP that she was depressed. The physical side effects of treatment were significant, affecting her ability to eat and her pain levels were high. Daphne's husband found it difficult to cope with her diagnosis and would not accompany her on hospital visits. She describes having a strong support network of friends and attributes this as being part of her ability to stay positive. She felt that she needed more help throughout her experience and would have liked a designated person to call with concerns; instead she felt that she had to wait until she came into clinic and this was a source of difficulty. The impact of changes to body image was significant as this affected how Daphne perceived herself and how she felt others saw her. Daphne was keen to give back to others after her own experience and felt that, as someone who had experienced haematological cancer, she could be useful to those going through it. Daphne was particularly vocal about the perceived lack of services available to haematology patients compared to other cancer patients, in particular breast cancer patients.

Super-Ordinate Themes

In total, six super-ordinate themes emerged from the analysis. Theme titles and their corresponding sub-ordinate themes are presented in Table 3.1. Following the table is an interpretative summary of each theme, including exemplar quotes.

Table 3.1: Overview of themes

Super-Ordinate Themes	Sub-Ordinate Themes
The Everyday Impact of Cancer	Practical; Physical
Psychological Needs	Adjustment Throughout the Cancer Experience; The Importance of Environment; Perceptions of Self; Specific Areas of Psychological Need
The Need to Feel Supported Throughout the Cancer Experience	Social Support; Feeling Supported by Medical Professionals; Availability and Acceptability of Psychological Support; Being Supported as a Haematology Patient
Barriers to Accessing Support	Feeling Unable to Ask for Help; Physical vs. Psychological; Psychosocial Concerns Not Discussed
Making Sense of the Cancer Experience	Personal Changes; Understanding My Experiences; Control
Need for Information	Delivery of Information; Having Personalised Information Available

The Everyday Impact of Cancer

Being diagnosed with haematological cancer has an impact upon how able patients are to maintain their everyday routine. Both physically and practically cancer can have huge repercussions and can impact upon daily functioning.

Practical

Practical needs were endorsed by all six participants. The type of need identified varied between participants but in general, being diagnosed with cancer meant that tasks that were either easily maintained before or had just not been considered a priority now became issues that required consideration:

"I was thinking only the other day that I need to update my will" David

"you could help at home but just... didn't feel like it. Just didn't seem to have... the energy" James

Sometimes the practical issues discussed became a concern because participants did not have prior knowledge of how the relevant systems work, and the lack of clarity both fed into a more general sense of uncertainty, but also created additional work and stress.

"You do need someone who knows the system to help you" William

Generally speaking, most of the minor practicalities associated with living with a diagnosis of cancer were described as being managed well by the hospital staff. Although practical concerns did arise throughout the course of their illness, generally these needs were deemed as being met which diminished any resulting psychological distress as a result of the presence of need.

"They do go to quite a lot of effort don't they to find out who you live with, who's there, what your property's like" Mark

Physical

Physical needs were repeatedly identified by participants. However, as with many practical issues, they were often deemed to have been met by the nursing staff.

"I would say, around the physical stuff there, the, um, a lot of that was dealt with by the nursing people on the ward" Mark

"Anything around, if you needed, you know, erm, the washing, the dressing, the sleeping stuff, yeah that was dealt with" Mark

On-going physical needs were still a concern for some participants and prevented them from doing the things that they would have liked to or had done before they were diagnosed.

"the pain, the pain was extraordinary" William

"Yes, the, the exhaustion does continue. I find that I can't do what I used to." Ray

This change from 'normality' seems to be what made physical needs difficult to manage yet there was an expectation that there would be physical consequences of having an illness such as cancer. This expectation that there would be both physical and practical effects of cancer lessened the impact of unmet need within these domains, and participants

generally seemed able to cope and to adjust to these needs, even where suffering was present.

"as you get older the physical needs and issues change regardless of how well you are" David

Psychological Needs

Adjustment Throughout the Cancer Experience

Being diagnosed with cancer was the first time that participant's had to acknowledge their own mortality and were forced to accept that their lives were going to change. The way in which patients received the news that they had cancer impacted upon how difficult the subsequent adjustment process was, with some describing rather blunt and brutal conversations with their HCPs which seemed to feed into a sense of feeling lost and uncertain.

"basically I sat in front of him and he said 'you've got cancer'… what you got is probably incurable, and you need to see a specialist. And then, off you go. So." David

While participants wanted to know what was wrong with them, the truth was always deemed to be important, the way in which this was communicated by the hospital staff was key. The point of diagnosis was traumatic for participants and often stood out as the worst point in their entire experience, as such being spoken to honestly, clearly and yet kindly was highly valued. Once diagnosed, the psychological impact of being a haematological cancer patient was felt immediately. For some, the negative connotations associated with having cancer and facing up to being ill was the most difficult hurdle to overcome.

"when they do tell you it's cancer… it knocks the wind out of your sails" James

For another participant however, there was a sense of relief to finally know what was wrong after having been told that there was nothing wrong by their GP:

"he (GP) said it was everything except, oh you've got depression, you've got this, you've got that…it was a hell of a relief to know there was something wrong, rather than me thinking it was…" Daphne

The end of treatment was also a crucial time in psychological adjustment. During the diagnosis and treatment process, patients are regularly visiting the hospital and have the security of seeing their clinicians regularly and being able to ask any questions that they

may have. Once treatment ended, this safety net is removed and people are then left to cope on their own.

"I think the emotional bit comes in right at the end to be honest with you… When you're in it and the treatment is there and you think, right, from here we're going to have chemo next, we're going to have this next, we'll have reconstructive stuff. And then when you get kind of fired off at the end. You're at home aren't you? Well, you are, and I think that maybe that's the time" Mark

Additionally, participants described putting everything into 'fighting' their illness, and then having nothing left to give once that process was complete. The 'fight' was over and the real impact of having had cancer became apparent.

"I just, having got the all clear and having got that letter, I just… just descended. I just couldn't face anything. And I don't know… I'd just given everything." Ray

Once cancer was 'over' and treatment completed, the sense of purpose and moving forward can become lost. There was a lack of certainty around what to expect after cancer, and the reduced level of contact with the hospital meant that there was less opportunity to speak to clinical staff or to seek reassurance.

"is that what we're supposed to expect after?" Daphne

A sense of uncertainty and isolation can permeate and leave patients feeling vulnerable and unsure of what will come next at a time when many patients feel that their lives should be returning to 'normal'.

The Importance of Environment

The environment in which care was given had a psychological impact upon participants. A physical environment that was seen as depressing, or one that was seen as a place for ill people to be, impacted negatively on participant's own sense of wellbeing:

"I did go to [hospital] on one occasion. And, I, I found it a very sad experience, I found it a very sad hospital. That… There were so many very ill people round there… And, er, I really didn't want to go back there, it depressed me no end that… experience." William

"once I was out of there, I was back to normal" James

The hospital ward setting is not always seen as being the best place in which to raise psychosocial concerns, a theme that is discussed in depth under 'Barriers to Accessing Support'. Given the reluctance of participants to discuss psychological concerns in the hospital clinic setting, it may be that a physically separate environment would be more conducive to patients feeling comfortable about broaching concerns of this nature.

“we do need to perhaps have a separate clinic, not necessarily in here but somewhere else in the hospital or somewhere else where you can come and talk to us about it” David

There was a feeling of separation between the physical illness that the hospital is deemed to be there to cure, and the psychological impact of living with such an illness. A sense of continuity and being physically comfortable was important in the enabling the treatment environment to become comfortable psychologically and, where present, this impacted positively on wellbeing.

"And the attitude changed... and that made a huge difference to me" Ray

"I always liked to be in the same place for my chemo, treated in the same little corner and sit and watch everything that’s going on." Ray

Perceptions of Self

Other people’s perceptions of their illness were important. There was a need felt by participants to keep positive and this meant that experiencing other people’s negativity was difficult. Patients need to believe that they will get better and any opinions to the contrary challenged this belief and make the belief more difficult to maintain.

“a lot of people think as soon as you’ve mentioned cancer, they think god, we’ll be burying him soon” James

The perceptions that others have of cancer, and that it is often equated with death, can also create a mis-match with the patient’s own expectations for their future and their recovery. This created a conflict with the need to think positively and to believe that they would get better, which is difficult when the patient is trying to think in a certain way about their illness.

"I didn't expect to die when I was give that, told I had cancer" David

There was also a sense that other people who haven’t experienced lymphoma don’t fully understand what it is like to live with cancer and, therefore, some of the views expressed by others or within the media seemed to antagonise, and to create distance between participants and those around them.

“everyone talks about, again, you know, the media, fighting… battling cancer, fighting cancer, so and so’s beaten cancer four times. Well, I… I don’t know what that means really.” Mark

The way that participants perceived other people's view of them to change as a result of their diagnosis fed through into perceived changes in the way that participants were treated by others and the degree to which they felt viewed as an individual rather than a patient.

"I've just been thinking about respect for the individual, as you were talking about that, I think, sometimes, when people are ill, some people see the illness and not the individual still. Um, I think, I'm hoping we've gone through this but I'm hoping, when HIV first came along and people saw HIV and not the individual. And I think that's an absolute travesty. You know, it's not the way it should be. And I think, sometimes, if you've had cancer, people see you as a cancer sufferer, or a recovering cancer sufferer, rather than as John or Fred or Mary or Jane or whoever you are… Who happens to have this, rather than, that's your defining element." David

This difference was a difficult thing for many participants to manage as it called into question further their perception of self and their role in the world. For participants who had viewed themselves as being powerful people, being treated as an 'ill' person was challenging, they did not identify with being an ill person.

"You know, I suppose in a way, I, I was always very, I'm amazed, you get some people in the newspaper now and they say, cancer survivor so and so, or there's a young girl in Chester who is constantly doing charity work cos she's a cancer survivor and stuff like this. Well, even at the time I was pretty touchy about it… I didn't want to be defined… as a cancer sufferer." Mark

For others, being treated with respect was difficult as it was felt that being diagnosed with cancer was something that happens to you, not something that is earned.

"Erm, I found the respect as an individual rather difficult. Erm, because, err… through the school, you know, I was going to beat that and they passed that information on to everybody else and I was getting messages from school and everything… and I did not see myself as being an inspiration to anybody." Ray

For some, being seen as a 'cancer patient' was something to be actively avoided. There was a strong desire to maintain appearances to others and any evidence to the contrary resulted in anger and frustration. Changes in appearance and the impact that this had on body image was a key concern for two participants, Mark and Daphne, in particular. Physical changes represent a physical manifestation of their disease, particularly difficult when someone strives not to be seen as cancer patient, as Mark did, and changes how the person feels about themself and how they believe that they are perceived by others.

"It made me so ill. It's taken me… this is my hair now, and I lost it two years last August. And this is all I've still got so you can imagine. Somebody who's been in fashion all their life with no hair. Erm… but the fact that I've never been as thin as this in my life, and so you feel a mess, a mess in clothes. And so I found it hard to, to… get going to put one foot in front of the other, I was just so exhausted… I just felt a freak" Daphne

There was a perception within this group of patients that, when compared with other issues related to cancer, body image should be something that matters less when compared to the potentially life threatening nature of the disease yet, physical appearance was something that really mattered to some as it is the way in which they present themselves to the world, an integral part of their identity.

"It matters what you... it matters to the person." Daphne

Specific Areas of Psychological Need

Psychological need was highly prevalent within the sample and an area where needs often went unmet. All participants identified some area within psychological needs that had been important to them during their experience. The impact of having unmet needs in this area was described as being significant, in one instance impacting so severely on a patient's life that he was still unable to live the life that he had had before being diagnosed with cancer.

"And I was in one hell of a state. Mentally. And, I still am." Ray

For others, the impact was less severe but having a diagnosis of cancer still impacted negatively upon psychological wellbeing and it was felt that the help available for psychological concerns was less accessible than for other issues:

"they're the ones which I felt most strongly and they're the ones which I didn't get any help with" Mark

Emotional

Having cancer was, at times, a highly emotional period of the participant's lives. Key events such as birthdays or Christmas seem to have been triggers for participants to realise the impact of their diagnosis and participant's described how this affected them emotionally.

"I can remember driving home from work on the motorway, and, I was crying while I was driving. And thinking 'I wonder how many more birthday's I'm going to have" David

Bursts of intense emotions were present even in those participants who describe themselves as accepting of their illness. For all, facing your own mortality forces the

confrontation of fears that otherwise remain unacknowledged and the desire to live comes to the fore.

Guilt was not something that was widely discussed within all of the focus groups nor was something that was explicitly asked about by the researcher. However, one participant described feelings of considerable guilt that had an on-going significant impact upon his psychological wellbeing.

"I still feel very guilty when I think of the time and I haven't made the most of the opportunities I have got" Ray

There was guilt at defying the expectations of being diagnosed with cancer, that is that one will become very ill and that death is highly likely. In turn, there were feelings around needing to make the most of life in light of being so lucky to still be alive which perhaps set unrealistic expectations of what life after cancer might look like which in turn fed into the presence of guilt around not being the hero who had survived cancer.

Coping

A range of coping strategies were described, each employed to help that person to come to terms with what was happening to them and the potential implications of having cancer. Some found talking about their experiences helpful and welcomed this. Others took part in voluntary work with relevant cancer charities, while not directly discussing their illness; this enables the person to be with others with similar experiences and to adjust to having cancer as a part of their life.

"the more I talk, the more I can, not come to terms with it but the more it settles into your psyche" David

In contrast, one person described trying not to get into emotional feelings about their cancer and actively avoided being seen as a cancer patient where possible in order to try to maintain as much of a sense of normality as possible.

"But it wasn't a Big Deal. Sorry, can I rephrase. I was a big deal cos I was away from home for too long and I wasn't at work and, you know, eventually went onto half pay at work and all this sort of stuff so it was a big deal in that sense. But... I couldn't get into that big emotional feeling" Mark

By maintaining the façade that things are fine, it may be that these participants found it easier to hold onto the belief that things are indeed so.

Fear of Recurrence

Fear of Recurrence (FoR) was an issue that was raised repeatedly within the focus groups as being a concern; however, there was a sense that participants felt that worrying about the cancer coming back was inevitable given their experiences.

“worries for the future, I can’t say that’s not a… you don’t want, you never want to face the facts do you” Daphne

There was also a sense from two participants that they were sure that their cancer would return. Whether this was based upon information provided by their clinicians or was in fact a way of coping with this concern by attempting to accept it is unclear. Both participants who expressed this view stated that they had been told that there was a possibility of recurrence but neither explicitly stated that they had been told this definitively.

"you have to get into a position mentally where you accept the recurrence, rather than fear it" David

The description of ‘accepting’ the sense of recurrence is telling as it indicates that taking this stance is a means of protecting the self from the possibility of recurrence to reduce the negative impact should this arise. The shock of diagnoses has been discussed as a notably difficult time for patients, anticipating a recurrence prevents re-experiencing a subsequent diagnosis in the same manner.

Hope/positivity

Keeping positive was a key need for participants. There appear to be several elements that were integral to this need: participants felt the need for positivity from those around them.

"you need people around you that, even if they don't think it, they need to show it that they've got a positive attitude" James

This was helpful in maintaining their own sense of positivity but participants also often described feeling unable to care for the psychological needs of others when they were feeling so overwhelmed and this understanding is undoubtedly related to their need for their supporting relatives to be positive and thus non-reliant on the patient.

Keeping positive and maintaining a positive outlook also appears to act as a way of coping for some participants, they need to maintain the hope and belief that they will get better as the alternative is to accept that death is a possibility and this would have a considerable negative impact on psychological wellbeing.

"my attitude right the way through was that I was going to beat it" Ray

The Need to Feel Supported Throughout the Cancer Experience

In general, support needs were noted as being important to participants and where this need was felt to be unmet, the impact was felt to be significant.

Social Support

The relationships held with family and close friends provided a great deal of emotional support and were highly valued. Being diagnosed with cancer had the potential to impact negatively upon relationships with some participants expressing surprise at how certain friends reacted to the news, providing less support than expected by the participant. This was a difficult thing to deal with and to not to have the expected support was challenging, particularly in light of how highly valued social relationships were.

"Yeah, it was really important, it really raised my spirits but, you know, as I say I was a little bit surprised really about who kind of put what into the pot in a sense." Mark

For some, the maintenance of social relationships became difficult throughout their experiences. The weight of their own concerns and distress was such that it became impossible to take on the distress of others also.

"I didn't want to make contact cos I just couldn't cope cos I was up to here" Daphne

This results in a reduced support network, the presence of which is known to be beneficial for patients.

Employment was felt to be an area where people might need significant support, however, most of the participants in this sample felt that their work related needs had been managed during their illness. Where the social support from colleagues was felt to be good, this had a positive impact on overall wellbeing:

"I have to say the office, they've been terrific." David

It was recognised though that, had this not been the case and had employers not been willing to accommodate their needs during their illness, then the potential implications both practically and psychologically were significant.

"As a group it's extremely relevant. Gaining and maintaining" David

Feeling Supported by Medical Professionals

Communication

Communication between participants and their healthcare professionals was crucial for determining how comfortable and supported participants felt with their future care. Successful communication was deemed to be when it was clear and tailored to the individual patient. Corresponding with the later theme on information needs, in order for patients to feel supported within the clinical environment, the way in which information was given had to be right.

"even though they kept explaining things… they use big words and names of stuff. If it was written down you'd probably be able to take it in easier" James

Having one key member of the medical team who could act as a point of contact was deemed to be beneficial as it would allow patients to build a relationship with that HCP and to be able to trust that they could approach them with any difficulties that they might have. This was not always felt to have been the case for participants, and the lack of a key worker was felt to be a barrier to being able to build a rapport with a member of staff which would have made it easier to know who to approach in a crisis.

"I just feel if only I had somebody like (nurse), like (nurse), somebody who would go through things with you… when you're desperate. That's what we're short of." Daphne

Communication between medical professionals was felt to be highly important in allowing patients to feel at ease with the decisions being made about their care and, when felt to be done well, created a sense of satisfaction for participants.

"the liaison between the surgeons and the consultants and this hospital and another… all of these columns, as I suppose you might expect, that's where I felt I had the greatest need and where I felt they were met most fully." Mark

When communication between HCPs and patients was not well achieved, however, it impacted negatively upon how the relationship was perceived.

"I said I'm not having any more [treatment], I've only come to see Dr (name). Anyway, next thing he comes and says you've got another six" Daphne

It was important that patients felt part of their treatment decision making process and that they were understood and their opinions valued by their treating clinicians.

Contact with hospital

Having regular contact with the healthcare professionals involved in their care was a key need for participants and creating a feeling of being supported by those providing care.

"I was coming in here every three weeks or every couple of months. And that was really helpful because you're constantly seeing the same people, who are experts in their field all the time" David

When regular contact ended at the end of treatment, the feelings of support that had been fostered during the treatment phase were suddenly absent, leaving participants feeling alone.

"And then you get fired off at the end. You're at home aren't you?" Mark

It is the contrast between perceived support during the treatment phase when hospital appointments are frequent and the end of treatment phase when this tails off that makes this a difficult time for patients. There is a need to feel that help is available if needed and regular contact facilitates this.

Treatment

As with diagnosis, the experience of being treated for their cancer was something that all participants talked about within the focus groups. This was a common experience for participants, even where the exact nature of the treatment given differed, all had had similar experiences of being treated at the hospital and the physical side-effects and uncertainty that this brought with it. Treatment was a topic where participants could feel sure of shared experiences, yet that did not seem to be a source of any embarrassment or discomfort making it an easy topic of conversation.

Treatment needs were present but the way that they were discussed indicated that they were an expected part of cancer treatment. This seems to lessen the psychological impact of having treatment related needs and fed into an increased ability to cope with concerns in this area.

"you expect the treatment to make you feel ill. That's what I found, when I started it, I expected to feel bad" David

That being said, there was a real need for support from HCPs during treatment. In particular, side-effects were noted as being are area where further support was needed.

"the side effects of the treatment. You need more help." Daphne

For some, the physical impact of treatment was high and there was a perception of insufficient support available outside of the hospital setting to manage unexpected effects that arose. While undergoing treatment, support was immediately available from staff administering, yet when patients went home between appointments, it was not clear when or who to contact for concerns as they come up.

Where treatment deviated from the expected model of treatment for cancer (i.e. chemotherapy, radiotherapy, surgery or a combination of all), it was challenging for the participant to make sense of the deviation from expected outcome.

"*One of the many aspects of this that I've found... challenging, in a way, is the watch and wait" David*

This lack of treatment goes against the perceived conventions for cancer treatment and the prolonged waiting to become progressively more ill made this time difficult. This feeds into a sense of uncertainty and anxiety both around what the future will look like but also allows fear around the cancer to develop and grow.

Availability and Acceptability of Psychological Support

There were differences in the extent to which participants would have been willing to engage with formal psychological support. Some felt that they would have benefitted from this kind of support while others were adamant that they did not feel that it was right for them.

"I'd rather have somebody prescribe something than deep, psycho, self analysis" Mark

The presence of unmet psychological needs did not appear to correspond with patient desire to seek or receive support for their needs, indeed, those participants who expressed unmet psychological needs were also, on occasion, those participants who stated that they did not want help with psychological concerns. There was a sense that participants thought that psychological support would be available to them if a patient directly asked for it, but the onus was seen to be on the patient to ask. Participants differed in how comfortable they would have felt doing so.

"you don't get any interaction with a psychologist or someone who understands these things, if you are feeling depressed, you would probably tend to keep it to yourself because you're sat in a room with 12 other people" David

It was also felt that it is unclear what kind of support would be available or offered, the uncertainty of which may feed into the reluctance to ask, giving rise to thoughts of "do I want that type of support that might be given?".

"they don't really advertise it to you much" James

The lack of understanding of what a psychology service can provide fed into the shared reluctance by some to consider these services as an acceptable support option. Better advertisement of the type of support available would demystify psychological input and would increase perceived acceptability for some patients.

While not all participants were comfortable with the idea of formal psychological support for themselves, there was a recognition that their families were in need of support and this was felt to be an area where there was a real lack of support.

"the family suffer worse… my wife still goes into tears over it" James

Concerns about those close to participants were prevalent and added a layer of complexity to the participant's own feelings and concerns regarding their illness. The wellbeing of patient's families directly feeds into the patient's own wellbeing as the family is often the primary support system and the patient is likely to be concerned about any distress that their family experiences as a result of their illness.

Being Supported as a Haematology Patient

Other people's understanding of haematological cancers

It was clear from each of the focus groups that haematology is perceived as being somehow different from other cancers. As a diagnosis, it was thought to be less well understood by both peers and other healthcare professionals which added to feelings of being different and being separated from other 'cancer patients'.

"they think cancer's cancer, and it isn't is it?" Mark

The psychological impact of feeling separated from others has the potential to be significant. The separation is potentially multi-layered with patients not identifying themselves as being 'cancer patients' yet nor can they feel a sense of understanding from their loved ones from whom they would previously have drawn on for support and comfort. This has the potential to produce feelings of isolation and vulnerability at a time when social support is known to be particularly important.

The perception of poor understanding of lymphoma extended from social circles to HCPs involved in patient care.

"I think the GPs should be taught a little bit more about lymphoma" Daphne

While the expert support from the haematology teams was generally deemed excellent at providing physical care for their illness, the level of understanding of lymphoma from primary care clinicians was often felt to be lacking. The GP is often the first person that a patient will come into contact with when becoming ill and feeling as though their clinician does not have an adequate level of knowledge of their condition can create feelings of anxiety and anger with the people who should be a source of support and reassurance.

Haematological cancers are different

Participants identified perceived differences between themselves as haematological cancer patients and cancer patients with other diagnoses.

"I'm in remission and, you know, hope to be so for as long as possible but, there's no outward signs. Now, if you've had aggressive breast cancer and, for instance, you've had a mastectomy… and your body image changes. Whereas here there isn't much to take away, it's all, it's more medicine as opposed to surgery and it's more like diabetes that's controlled" David

There are differences in the way that haematological cancers are treated; David likened his treatment to that of a chronic diagnosis rather than the 'surgical' approach that he felt was more commonly associated with cancer treatment.

"they say, you've got cancer, we're not going to do anything about it" David

This deviation from the expected had a psychological impact that patients may not have anticipated when initially given their diagnoses. Watch and wait requires on-going monitoring of a patient's condition but no active treatment is undertaken until the patient becomes symptomatic. Commencing treatment brings with it a sense of 'fighting' the disease, something that has become part of the general stance regarding what a patient *should* be doing when they are diagnosed with cancer. Not only does a lack of active treatment take this sense of purpose and moving forward away from patients, it also requires them to wait in the knowledge that, at some unknown time, their illness will progress and they will become ill. Information about what to expect is provided but the individualistic nature of cancer means waiting for something that is not fully comprehended yet perceived to be negative.

Even where active treatment was undertaken, the nature of haematological cancer treatment meant that a sense of ambiguity remained.

"but once, with breast cancer, once they take it away it makes a big difference" Daphne

With the haematological cancers, surgery is much less common than for solid tumours with many patients being treated with chemotherapy alone. One participant described feeling as though surgery would have been preferable as this would have enabled her to feel as though her cancer had been removed, a perception that was not forthcoming with chemotherapy alone. When a cancer of the blood and bone marrow is diagnosed, patients can feel as though the cancer is everywhere and has taken over their body. This can mean that patients do not get the sense that their cancer has been removed and continue to feel as though their bodies have been invaded by this malevolent being.

This difference in treatment also translated to differences in appearance when compared to what might be 'expected' of cancer patients. Feeling 'different' in this way may act to impact upon how isolated patients feel during their illness, compounding any feelings that personal relationships are affected by diagnosis.

"what I think is interesting about this particular disease is that you don't actually look ill" David

The absence of altered appearance resulted in difficulties for both the patients themselves and those around them to perceive them as a 'cancer patient'.

"it is easy to sort of internalise them, and it's easy to ignore them and, erm, for others to ignore them if you like" David

For some, this would have been a positive as it means that they were more easily able to maintain a sense of normality. For others, being diagnosed with cancer was a highly significant event in their lives and while they may not have wanted to continually engage with thoughts about cancer, it was important that the significance of what was happening to them was recognised.

Support available

The reduced awareness of haematological diagnoses and the inherent differences combined to create the perception that, as haematological cancer patients, they were less well catered for in terms of the level of support available.

"Now if you've got cancer, the Macmillan nurses are superb" Daphne

The use of the phrase “if you’ve got cancer” is notable, again indicating a lack of identification with the self as a cancer patient. Rather, patients seem to feel that they have their own distinct identity as a haematology patient.

The perceived lack of support was compounded by comparisons made with the level of support available to other diagnoses, with breast cancer being given as an example.

“If you’ve got breast cancer, you get a lot more… erm… cushioning.” Daphne

The sense that they are different and that this means less support was challenging for participants. Daphne in particular felt a sense of unfairness that there was so much support available for some patients but not for her as a haematology patient. This acts to feed to sense of isolation and difference from other, potentially resulting in heightened emotions for a group that do not feel willing or able to access psychological support.

Giving something back

As patients now in remission, participants described feeling the desire to give something back and to help others now in the situation that they themselves had previously experienced.

"I did this whole school assembly once, I just said to all the kids, look... I woke up one morning and had a lump the size of an orange on my shoulder" Mark

This desire to help others with their illness may stem from their own sense of being different and the resulting feelings of isolation experienced, participants did not want others to have to go through the same experience as they had.

"I go along to show people that it's not just people in their 70s that suffer from this" David

Being able to provide support for others is also likely to be a source of comfort and support for patients themselves. Although their disease may be in remission, feelings of being somehow different are more persistent and spending time with others in the same situation can lessen feelings of isolation and provide comfort in its own right.

Barriers to Accessing Support

Feeling Unable to Ask for Help

Participants described feeling unable to raise psychological concerns with healthcare professionals, it was not a comfortable topic for participants.

"When you're not used to doing that, and perhaps not comfortable with doing that" William

This problem may be exacerbated by the fact that this sample was predominately composed of older men, an age group that are perhaps unused to discussing their feelings and emotions with other people. The business of the ward environment was not conducive in enabling people to ask for help. If someone is not comfortable talking about their emotions, then trying to do so in an environment where there are a lot of people present and where the staff are obviously busy, there is a fear that they would be either disturbing the staff member or that their concerns are simply not important enough, and this acted as a real barrier to psychosocial concerns being raised.

"I think the support is there if you, you want it. You just ask. But I think sometimes, do you not think people are afraid to ask? In case, because everyone's busy, I think some people get it in their head, oh I can't, I'd better not ask in case they're busy" Mark

There was a perception held by participants that asking for help with a concern that was not physical in nature was somehow less valid that a directly medical concern, again reducing the likelihood of patients seeking help. Hospitals were viewed as places where illness is treated medically, and anything that fell outside of this remit became an area of uncertainty.

"But I was reluctant because... pride. Erm, but yes I think you cover a lot up." Daphne

There was a sense that not to be coping well with illness was somehow shameful. Feeling too proud to admit to struggling, or feeling as though you should be able to cope, were obstructions to open and frank discussions around psychosocial issues.

Physical vs. Psychological Concerns

The clinic environment was noted to be busy and full of other people with HCPs being incredibly busy trying to provide assistance to large numbers of patients. When patients are already uncomfortable with raising a concern, doing so in front of many others felt almost impossible.

"I don't know if you've been to clinic here recently, there's a hundred people out there" David

The medical staff at the hospital were held in high esteem by all participants, however, this may actually have compounded the feelings of discomfort around asking for psychological help as patients feel concerned about 'troubling' staff when they are perceived to be too busy.

"I kept saying that I, I'm sorry, I don't like troubling you" William

Again, there is a sense that psychological concerns are just not important enough to 'bother' HCPs who are busy doing things that are of perceived greater importance. There seems to be a perception that hospitals are for treating physical illness and there was an uncertainty about whether it was OK to discuss other issues with hospital staff. In addition, where other patients were seen to be struggling physically, it was deemed unfair to ask the staff to deal with psychological issues rather than the physical ones.

"I was so grateful and so lucky that in my first session of chemo all I got… And to see other people there… how can I be dragging nurses away from them to deal with the way I was thinking about things, not feeling, but thinking about things? It just didn't come into the equation." Ray

Psychosocial Concerns Not Discussed

As a consequence of patients feeling uncomfortable asking for help and having the perception that the staff are either too busy or that psychological issues are less valid than physical concerns, psychosocial fears were simply not discussed.

"I was just sitting there listening, reading my paper, being as jolly as possible when someone came round so, maybe they thought, well this is a guy who doesn't seem to be presenting as anything" Mark

Patients don't feel able to raise their concerns and described putting on a 'brave face' but then this meant that the healthcare professionals were unaware that a problem existed and did not raise psychosocial issues either.

"unless they've got time to spend speaking to you, they cannot hear what's happening inside you. And it's the bits you can't see." Ray

The result of this was that psychosocial concerns were simply not discussed within the clinic setting. This meant that the impact of psychological or emotional needs was able to develop and become more problematic as the needs grew in the absence of support from the hospital.

Making Sense of the Cancer Experience

Personal Changes

While cancer was generally deemed to have been a negative experience, there were instances where participants chose to look for the positive in what they had been through. Personal growth as a result of living through their illness was one such benefit.

"it kind of makes you a different person at the end of it" David

Participants felt that having faced their own mortality, they now had a clarity in their lives that had not been there before and, as a result, chose to live a life that was closer to how they had always hoped it would be. Priorities became clearer and it was easier to put what mattered to each person first without feeling apologetic about doing so as the awareness that life is not infinite had been harshly realised.

Understanding My Experiences

Throughout the focus groups, participants formed comparisons with others in such a way that seemed to play a role in helping them understand their own experiences. Creating positive comparisons with others who have survived the illness was a way of providing hope and reassurance that their situation was not as bad as it could be.

"I went along to my first support group at the Lymphoma Association and there's a lady there who was diagnosed with NHL 18 years ago" David

But, conversely, to see other people pass away as a result of their illness was difficult for participants to cope with and contradicted the need to remain positive and to believe that they would get better.

"So she said… oh, anyway, unfortunately (name) was dying. Now can you imagine going through all this and thinking she's just told me two years." Daphne

While seeing others survive and thrive after cancer was a powerful source of hope, seeing others struggle throughout their illness was not only difficult in that it caused participants to acknowledge the possibility of death but also it meant that participants had to rate themselves on a sort of scale of how well they were coping with their illness in comparison with others.

"looking at others, and the way that some people would only get halfway through their first lot of the day and be really struggling..." Ray

"my problem was a tiny one" Daphne

Comparisons caused participants to feel as though their concerns were minor in comparison but this also had the adverse effect of creating feelings of guilt that they felt how they did when others were perceived to be coping with worse. This also fed back into a reluctance to speak to staff about psychological concerns, these problems were deemed to be insignificant in comparison to the physical suffering that others were experiencing.

Control

Taking control

Taking control of one's own care emerged strongly as being important to some participants. In such a potentially uncertain time where outcomes were so unsure, it was important for some to be able to find a sense of control wherever possible and for some that was by taking control of their own medical care.

"that's when I referred myself to (Dr), because they couldn't find me a haematologist within about, two months, which I didn't think was good enough" David

For David, the care that he received at the very start of his illness experience was deemed unsatisfactory and, as such, he made the decision to seek out his own healthcare privately. This is a rather dramatic example of a patient taking direct control over their experiences but smaller instances of needing to feel in control of your own body and illness became evident.

"I went for a number two (hair cut), because I thought I'm not going to go around looking like tufty" William

There was variation in where participants appear to place the locus of control for their treatment and recovery. Some participants took an active role in their own care while others deferred to the perceived expertise of their clinicians.

"There's nothing you can do about it, you're in the hands of other people who will hopefully do the right thing for you" David

This quote also came from David, the patient who took such significant control over his treatment at the start of his illness, suggesting that the ability of the patient to let their HCPs take charge is something that is built on trust. Where the patient feels able to trust in their treating clinician and the competence of those involved in their care, the need to be in such overwhelming control of treatment decisions diminishes. This is likely to have a positive impact on patient psychological wellbeing, to have faith in HCPs, and to trust that they will make the best decisions for them thereby taking the onus off the patient to be in charge during such a vulnerable time.

"the doctors will go in and sort it out, that was my attitude" Mark

This same sentiment was echoed by other participants who also reported a strong need to be in control of their own situation and to maintain their prior roles. The need to feel in

control appears to diminish over time, perhaps in direct correlation with the development of a relationship with the patient's HCPs.

Feeling in control as coping mechanisms

Control, both taking control directly and seeking out knowledge in order to enhance understanding as a way of feeling more in control, can be framed as coping mechanisms.

The need to feel in control of one's own treatment has already been highlighted above but this can be framed not only as a need which is important to many patients, but as a coping strategy that allows patients to feel as though they are coping with and managing their illness.

"I did feel as if we knew exactly where we were and what the next step was, and broadly what the significance of every part of the intervention was really" Mark

Cancer patients regularly describe wanting to know as much as possible about their illness and treatment, and information needs will be discussed separately as a theme in their own right, but again this need feeds into a sense of gathering knowledge as a way to feel in control and to try to understand what is happening, that again functions as a coping mechanism for many patients.

"If it's... cancer... so what? I know where I am." Ray

There was a feeling within the sample that knowledge and understanding reduced levels of anxiety and that as long as patients knew what their current prognosis and treatment plans were, then they could start to process and to come to terms with their illness. It was uncertainty that was the root of many anxieties and even worst case scenarios can compare favourably than being left in a state of not knowing.

Need for Information

Delivery of Information

Participants raised the issue of how information was presented to them. Generally it was felt that the way that information was given was appropriate

"that's fine with me, you know that's the way I want the information" Ray

And the provision of information had a positive impact of reassurance for many, allowing them to feel as though they knew what to expect and what was coming next.

"he went through it all and explained it all to me and what was going to happen" William

However, some participants felt that info could have been delivered in a more helpful way. It wasn't always clear and the use of medicalised terminology meant that it was too complex to understand

"words of one syllable… and plain, simple English" James

So, in this case it is likely that whilst information was sought as a way to reduce need, the impact would have been minimal – the information was not presented in a helpful way and so the need would not be reduced.

Having Personalised Information Available

Having information about diagnosis and treatment was highly valued but it was felt that there was a need to receive information that was tailored to their individual circumstances rather than generic information given to everybody. In addition, it was felt that there needed to be some clinical judgement displayed by the clinician that determines when information is provided.

"they also give you the five to ten year prognosis, which is, not very helpful when you're forty-something" David

Information needed to be relevant to each person and focussed on the patient's most immediate concerns.

"when you first start you get all these generic leaflets on you know, how do you get a wig, I don't need a wig, what's going to happen if, what's the likely side effect." Mark

While it was acknowledged that HCPs often had to present patients with the worst case scenario, it was also felt that simply being told the general statistics for your illness without taking into account the specific age and stage of the patient was unhelpful as it did not necessarily reflect the most likely prognosis.

"for me it was understanding as well as I could, exactly what was happening to me" David

As already outlined, having sufficient information to be able to feel that you understand your own illness and treatment plan was found to be highly beneficial for patients and fed into the presence of a sense of being in control.

"I think you get as much information as you, as you ask for. As you can handle." Mark

It was felt that there needs to be a balance of being given sufficient information to be able to feel that you understand what is going to happen without being given too much negative information that could potentially make the patient lose their sense of hope.

"there has got to be a happy medium" William

Participants advocated the provision of information as being staged. In the beginning, there is an immediate requirement for information about the diagnosis and likely treatment, but not necessarily much beyond that as patients found it difficult to take in large quantities of information after receiving such devastating news.

"so if you then see any of those signs and symptoms, you can then ask for the information to deal with that as a result" Ray

It was deemed important, however, that access to relevant information was available as and when it was needed, and that patients should be clear about what resources they have available to them.

The Most Commonly Reported Unmet Needs

At the end of each focus group, participants were asked to highlight the needs that were most important to them during their illness on the prompt sheets used to stimulate discussion during the focus group (see Table 3.2). For the complete table of unmet needs highlighted as being most important for each participant, see Appendix 6.

Table 3.2: Number of times an unmet need within each domain was ranked as important.

Area of need	Number of times individual needs within a category were highlighted
Physical	17
Psychological	13
Identity	2
Social	4
Practical	5
Medical	12
Information	7
Communication	4
Cognitive	2
Employment	1
Financial	3
Spiritual	1

Table 3.3: The most commonly cited unmet needs and number of participants who endorsed the need as important.

Unmet Need	Times Highlighted
Having a key worker	4
Understandable info	4
Keeping positive	5
Fatigue	4
Eating related	3
Fear of recurrence	3

Physical needs were the most commonly endorsed (17), followed by psychological needs (13). The three most commonly endorsed individual needs were: keeping positive (5); having a key worker (4); and receiving understandable information (4). These needs fall within the psychological, medical and information categories respectively. The most commonly identified need was the need to keep positive, a psychological need. Maintaining a positive mind-set throughout was felt to be instrumental in how participants experienced their illnesses. Fear of recurrence, fatigue and eating-related concerns were also highlighted as a concern by at least half of the sample.

The greatest number of unmet needs individually highlighted fell within the physical domain, followed by unmet needs in the psychological domain. Between them, these two areas represent where our participants had the greatest concerns during their experience. There are differences however, between physical and psychological needs, both in the way that participants understand these needs and the impact that they were felt to have. Physical needs were felt to have been present but, in general, were more often met as part of the routine care provided by the hospital. Physical needs also seem to have less of a negative impact than the presence of unmet psychological needs. This may be attributable to the fact that participants described expecting to experience physical changes and discomfort when they were diagnosed with cancer. Unmet physical needs were therefore viewed as a normal part of the cancer experience and were something that participants felt comfortable addressing with their healthcare professionals. Conversely, the presence of psychological needs was less well anticipated by participants and so the negative impact was more profound. In addition, these needs tended to be less likely to be met. This is likely to be attributable to psychological distress not being viewed by participants as an integral part of the cancer experience in the way that physical needs were, and so these needs were less often addressed with healthcare professionals at the hospital.

Discussion

This qualitative study aimed to examine the experiences of unmet needs of adults with a diagnosis of haematological cancer using an analysis of existing needs measures as a starting point. The findings from the systematic review detailed in Chapter 2 demonstrated a paucity of research relating to unmet need within this patient group yet the concept of unmet need has been often explored within other groups in the psycho-oncology literature. The findings from this study indicate the presence of similarities in the experiences and needs of haematology patients to those of other cancer groups, yet key differences were also highlighted. Six super-ordinate themes were identified, representing areas that were of particular importance to participants with key issues worthy of discussion emerging. In addition, the findings of this study can be applied to the appropriate assessment of unmet need in haematological cancer patients: if we understand the type of unmet need likely to arise and the relevance to a patient group, then the assessment of need can be equally relevant and tailored to that group of patients.

The Distinct Challenges of Being a Haematology Patient

There were recurrent indications that participants felt themselves to be different as haematology patients from those who were perceived to be 'cancer patients'. These perceived differences were a cause of frustration and feelings of isolation, resulting from perceptions of being less well understood by others and less well catered for within the cancer setting. Feelings of isolation or loneliness as a result of a cancer diagnosis have been highlighted previously (Macmillan, 2013; Helgason et al., 2001; Refsgaard & Frederikson, 2013), yet this has commonly been in relation to changing lifestyles or altered relationships with significant others. Across this sample no participant identified themselves as a 'cancer patient'. For some, the issue was around not wanting to be perceived as being ill or different to the person that they had been before and having a cancer diagnosis caused feelings of no longer being the person they had once been and wished to be still. For others, they clearly felt that they were a lymphoma patient, not a cancer patient. For these participants, there were innate differences between the two groups. What is novel about this finding is the sense of isolation from other cancer patients as opposed to the wider community. Feeling different from people who don't have cancer may be to be expected, but feeling different from other cancer patients has not been observed previously.

Previous research has advocated attendance at support groups to combat feelings of isolation during cancer. Shared experiences have been shown to reduce feelings of loneliness and provide a sense of acceptability and community (Ussher et al., 2006). The application of this finding may be problematic however, for a group of patients who do not cite a sense of belonging with the group for whom support groups are intended. Not feeling a sense of belonging with this identified group impacted upon the perceived applicability and acceptability of support services that are targeted at 'cancer patients', a finding that has not previously been explored within the haematological malignancy literature. No participants reported taking part in groups or services that had been set up to support cancer patients, where support was accessed from outside of the medical team, it was in the form of haematology specific support groups or charities. Choosing not to attend a support group is not in itself unusual for cancer patients, research has shown that very few attend groups of this nature (Grande, Myers & Sutton, 2006), however previously explored reasons for non-attendance have typically centred on why people choose to attend and who is more likely to attend (e.g. Taylor et al., 1986; Krizek et al., 1999) rather than who the support groups were perceived to be targeted at. For this sample in particular, there may have been specific barriers in place. The haematology oncology ward is physically separated from the oncology unit, creating a physical and seemingly psychological barrier between the two groups. As a result, even where participants had offers of support made to them, because those services were labelled as being for cancer patients, there was uncertainty around whether they were actually able to attend or whether those services would be adequate in meeting their needs. It is also worth noting that the sample was predominantly male and previously females have been found to be more likely to attend support groups (Grande et al., 2006). Grande also found that patients who already had access to formal support were more likely to attend a support group, and this access was felt to be lacking by patients in this sample.

Patients reported feeling uncomfortable about raising psychosocial issues with their clinicians but clinicians also did not typically raise these kinds of concerns, implying that psychosocial concerns often simply weren't discussed. It has been recognised that clinicians can find it difficult to raise psychological issues with patients, yet NICE (2004) proposed a model of stepped-care to illustrate how clinicians at all levels can contribute to the maintenance of psychological wellbeing in cancer patients. Training packages have been developed that aim to improve clinician efficacy at detecting and managing distress within a general healthcare setting (Merckaert et al., 2005; Fallowfield et al., 2002). While

these kinds of training programmes do seem to improve clinician confidence in their abilities and short-term competence (Fallowfield et al., 2003), there is less convincing evidence as to whether there are also improvements in ability to accurately detect distress or whether ultimately patient experience is improved (Moorey, 2013). The idea that cancer professionals do not always accurately detect the presence of psychological morbidity is not new (e.g. Fallowfield, Ratcliffe, Jenkins & Saul, 2001) and further work is needed to extrapolate the current evidence base in order to improve clinician confidence in raising psychological concerns with patients and to ultimately improve patient experience.

The Process of Adjustment

Experiencing cancer brings distinct challenges and for participants within this study there were pivotal moments in the on-going process of adjustment, beginning at the time of diagnosis. Being diagnosed with cancer was distressing for participants, marking the end of their current life as they know it and fundamentally altering their understanding of their world and how they feel perceived by others. It is well recognised that diagnosis can be a time of shock and distress for both patients and their families (Turner et al., 2005; Edwards & Clarke, 2004). The delivery of appropriate information was of utmost importance to allow patients to develop an understanding of their illness, likely futures and to feel supported (Parker et al., 2001), the first step in adjusting to their new lives. The way in which information is delivered at the time of a cancer diagnosis is highly individual and needs differ between patients (Schofield et al., 2003), and, when perceived to have been done well, patient experience and coping have been found to improve (Pollock et al., 2008).

After the initial diagnosis, all participants received treatment for their disease, whether immediately or after a period of watchful waiting. The physical impact of treatment, or the perception of, varied across the sample but generally this was a time when participants felt supported due to frequent contact with HCPs. Once treatment ended, however, the level of support available to participants was felt to drop away without allowing participants time to acclimatise which was felt by participants to be difficult to manage. While research relating to the unmet needs of haematology patients is scarce, it has been suggested that in the 12 months after treatment is completed new needs emerge or existing ones remain unresolved (Lobb et al., 2009). The time taken to regain a new sense of normality was unexpected for participants in this sample, and the gulf between perception and reality impacted strongly. The realisation that their previous life was no longer had a lasting

impact, one that was not felt to be supported by the healthcare system. Maintaining a sense of normality and the creation of a new 'normal' after cancer has been the subject of much attention within the related literature (e.g. Denford et al., 2011; Ekman et al., 2004). It has been proposed that being able to find a sense of meaning during stressful life events is essential for successful adjustment (Park, 2010). Where patient's appraisals of a situation do not fit well with their overall global belief systems, the ability to find constructive meaning in a situation is impaired and adjustment hampered. While ultimately, most participants had come to terms with their new 'normal', the process of adjustment to get there was more complex than had been anticipated which brings with it specific worries and concerns that are not currently well supported.

The Language of Cancer

The language used by participants throughout the focus groups provided some interesting insights into the way that they were thinking about their cancer. Language can be a divisive subject for both cancer patients and researchers. Even the term 'cancer survivor', one that has been taken on board by researchers and cancer charities alike, can have different meanings for patients. Many simply do not associate themselves with the term, either because of their perceived level of on-going threat or their thinking styles. Often language used by participants in this study was emotive (brutal; freak; butcher; scared to death; tears were streaming), which was indicative of the level of emotion participant's experiences of cancer. One participant talked about receiving their prognosis as waiting to hear the 'verdict', a term more associated with a legal environment than a medical one. At other times, the language used took on a fighting quality, or 'struggle language' (Seale, 2001). Words like 'fight', 'battle' and 'mustard gas' were all used by participants to describe their cancer experience. This symbolises the level of trauma associated with having cancer, to liken it to a war-like environment, but also ties into participants' need to hope and the need to place the locus of control with the self rather than believe that their cancer and their prognosis was something outside of their control.

The use of metaphors and fighting language is not unusual in the public discourse around cancer, yet is something that can divide opinion and evoke strong feelings in patients (Reisfield & Wilson, 2004) and clinicians. Ever since President Nixon declared 'war on cancer' in 1971, naming the disease as the 'enemy', the use of military metaphors has permeated the discourse around cancer. However, it has been proposed that using words such as 'battle', 'fight' or 'conquer' can place the onus on overcoming the disease on the

patient, in turn potentially creating feelings of guilt and shame at not having fought hard enough (Hulbert-Williams et al., 2014; Taylor, 1983; Sontag, 1978). In addition, contextualising cancer as a fight or a battle, places an assumption upon the patient's perception of their illness that may not be reflective of their actual views of the situation. There was a real dislike by some participants of words such as 'battling' or 'fighting' when used in connection with how they were coping with their illness. It was felt as though this implied a feeling that was not present and that actually words such as this misrepresent what it meant to those participants to really be a cancer patient. These participants, Mark most notably, argued that they were simply trying to live and to imply anything else was inaccurate and to be rebelled against.

There is also the risk that such terminology highlights the negative aspects of the cancer experience (Hayes et al., 2011). The notion that one must fight cancer and that to 'keep positive' is in itself a sign of positive adjustment to illness has become so entrenched into societies understanding of cancer, that there is an associated expectation of those living with the disease to act in this way or to be deemed as not adjusting well (Hulbert-Williams et al., 2014). There is a danger that patients will simply use language of this nature because this is what is expected, and that those around them will understand this to mean that they are coping well when in fact this language is simply compliance behaviour (Hulbert-Williams et al., 2014).

Differences Between Participants

While the sample of the study was relatively homogenous, there were some distinct differences between participants. Psychological needs were one of the areas of unmet needs that were ranked highest by participants, yet the desire to actively engage with formal psychological support to meet these needs was variable. One participant, Mark, was adamant that speaking to "an employee" from the hospital would not be beneficial to them and they were not willing to engage with this kind of support. Not wishing to engage with formal psychological support services is not a new findings (Baker-Glenn et al., 2011), indeed it is well recognised that the presence of psychological morbidity does not always equate to a desire for help. Another participant, Ray, had very different perceptions of psychological support and actively sought this out but described being unable to access the desired support via the hospital. Other participants, when asked about psychological needs expressed an interest although this was not something that was actively sought during their treatment.

Body image as an unmet need differed in the degree to which participants felt that it was important to them. For some, body image and the changes to their body and appearance that occurred as a result of treatment caused distress and impacted upon their self-confidence and perceptions of how they were viewed by others. Changes in bodily appearance represented being ill and were a physical manifestation of the disease, something that was unwelcomed by participants. Previous research in breast cancer patients has highlighted the impact that cancer and its treatment can have upon women's body image (Kraus, 1993), their self-esteem (Anderson & Johnson, 1993), and their long-term distress levels (Przezdziecki et al., 2013). Changes in appearance can also represent a difference between the person that participants have previously perceived themselves as being and the person that they feel that they are seen as now. One participant, Daphne, described having worked in fashion all their life, and how, for someone who has been in that environment, changes to the way that they look were difficult. For another participant, Mark, the loss of their hair was the main cause of distress as not only was this felt to be a physical sign of their illness, something that they were anxious to avoid, but also it was felt to change the way that other perceived them. Having a skinhead was associated with a certain type of behaviour for this person and this was not felt to be in line with that person's own perception of themself. For the remaining four participants, body image was not identified as a key concern and was an expected aspect of cancer treatment.

The degree to which having had cancer was continuing to impact upon participants appeared to differ considerably across the sample. Two participants expressed on-going difficulties that affected their everyday lives, Ray and Daphne, with Ray reporting considerable on-going distress as a result. This is in line with the finding by Lobb (2009), that unmet needs persist after treatment has ended and patients enter the survivorship phase of their illness. The remaining participants reported regaining a sense of normality in their lives, albeit in a different way to what was deemed 'normal' pre-cancer. Again, this is to be expected. Previous literature that examines unmet needs in cancer survivors has demonstrated that while the presence of need is problematic for some, there will also be a sub-group of patients for whom on-going unmet needs are not a concern (Harrison et al., 2009; Armes et al., 2009).

There were some very different feelings about being seen as a cancer patient across the sample and the way in which participants identified with this title. For Mark, having cancer was a temporary concern and not something they wished to be viewed as or associated

with. Strong feelings were expressed by him that having cancer was simply something that had happened to them but that was not permanent and was not part of who they were. Therefore anything associated with being a cancer patient was avoided. For other participants, having had cancer was something that was assimilated into their lives and their perceptions of themselves. While having had cancer did not define them, it became part of who they were and several participants expressed a wish to use their experiences to help others in a similar situation. For some, helping others meant that they would be willing to get involved in direct peer support, getting involved with haematological cancer charities or even acting as a patient representative for a NICE committee.

As participants differed in the way in which they perceived their status as a cancer patient, they also differed in the way in which they took control over their experience. Some patients actively tried to play an active role in their own care, either by feeling that they were engaging in a dialogue with their clinicians and seeking as much information as possible about their illness or by getting involved in the policy of cancer treatment by attending a NICE committee as a patient representative. For others, control was placed with their healthcare professionals and the belief that the doctors would do what they thought best for them was expressed. While not taking an active role in their own care, this could still represent those participants taking control of their experience by placing the control and decisions in the hands of those perceived to be the experts.

How does this work affect our understanding of why specific needs are important to patients?

Qualitative research can add a depth to findings that is difficult to achieve in quantitative work (Pope & Mays, 1995). Looking just at the number of needs highlighted as important to participants on their rating charts, physical and psychological needs are both identified as key areas of unmet needs for patients. Qualitative discussion within the focus groups around needs however, indicated that while physical needs were present, often these needs were met by the healthcare team involved in that patient's care and therefore would require no further intervention. Conversely, psychological needs were present but, unlike the physical needs, largely remained unmet, highlighting the insight that qualitative exploration of a subject can provide.

Understanding not just that psychological needs are present and unmet for patients, but being able to gain a clearer picture of the barriers to accessing support provides a novel insight and creates questions around the most appropriate provision of services. The

theme 'barriers to support' raises potential questions about the most appropriate setting for psychosocial support to be provided. As one participant stated, "we do need to perhaps have a separate clinic, not necessarily in here but somewhere else in the hospital or somewhere else where you can come and talk to us about it". The hospital ward is seen as an environment in which staff are there tend to physical ailments and there is some uncertainty about how acceptable it is to discuss psychological concerns with these medical staff (Ozacinci et al., *under review*). Even where distress is recognised in the clinical setting, only for a sub-group of patients does this recognition translate to a referral to psychosocial support services (Keller et al., 2004). In addition, the busy clinic setting and short appointment times compounded the feeling that the hospital ward is not the right place in which to talk about psychological wellbeing.

The hospital from which participants were recruited consists as a hospital building only and does not have a dedicated psychology service, either in the building or separately, although there is a Liaison Psychiatry service. There is a Macmillan centre within the hospital but this not always open and, given the concerns that participants have about the suitability of current support services meeting their needs, it is unclear to what extent patients feel that this is an accessible resource. This is not unusual within hospitals in the UK, particularly the smaller district general hospitals. There is an increasing recognition that cancer patients may require a more dedicated support service that is staffed by professionals with a specific expertise in supporting this patient group and that many unmet needs may lie beyond the remit of the treating services (Soothill et al., 2001). There have been a number of political statements and healthcare initiatives that have aimed to improve the psychosocial care of cancer patients (Surbone et al., 2009), and over a decade ago NICE released guidance that stressed the importance of supportive care for cancer patients (2004). However, the ongoing presence of unmet psychosocial needs and lack of a coherent strategy for the meeting of these needs within our healthcare system suggests that these measures have not had the desired impact upon patient experience. While participants in this study accepted that they experienced unmet psychological needs, in general the number of cancer patients who would voluntarily engage with a psychological or psychiatric service is low. This work highlights not just that psychological needs are prevalent, but also suggests areas in which improvements must be made in order to make support services acceptable to patients.

How suitable are current needs assessment tools?

The tables of needs identified from the thematic analysis of existing needs assessment tools can be compared with the themes to emerge from the focus groups to determine to what extent the two overlap. In general, the needs identified by participants were similar to the needs identified by previous needs assessment tools. There were however, needs that were not endorsed by any of the participants. No needs within the sexual or spiritual needs categories were endorsed by participants during the interviews; it could simply be that sexual and spiritual needs only arise in a smaller proportion of patients. Alternatively, this could be an issue with the self-report nature of needs assessment: it is well-recognised that self-report of sexual behaviour can be unreliable (Schroder et al., 2003; Fenton et al., 2000).

Across the sample, there are many similarities in the needs identified by this haematology sample when compared with the existing knowledge relating to unmet needs in general cancer samples (Harrison et al., 2009; Richardson et al., 2007; Morrison et al., 2012) with physical, psychological information and healthcare professional-related needs all felt to be relevant by participants in this study. This provides an indication that existing needs assessment tools are likely to be suitable for assessing the needs of this patient group, and, moving forward in this research, existing measures are likely to be appropriate for further quantitative work. The work presented in this chapter indicates that the differences between haematology patients and wider cancer groups are not in the type of need experienced, but rather in the perceptions of what it means to be a cancer patient, or indeed a lymphoma patient.

Limitations

There are both benefits and limitations of conducting a study with a small sample size. The intention of this study was to better understand patient experiences of need during cancer and how unmet needs impacted upon overall wellbeing; however, this does mean that the results are more difficult in terms of applicability across the whole patient population. Indeed, given the qualitative epistemology of this study (Smith et al., 1997; Smith, 2004), application of the findings to a whole patient population was not the objective of the work. Rather, this study was designed to provide a depth and richness that could fit alongside subsequent quantitative works from which wider generalisation could be inferred.

While the interview schedule was designed to encourage open discussion, the use of the item pool drawn from existing assessment tools had the potential to influence the direction

of the discussions held within the focus groups. Attempts were made to minimise this by firstly: not introducing participants to the item pool until part way through the interview to allow for unprompted discussion initially; for the analysis of the data to be open and not structured around existing needs, rather the analysis was entirely open as the researcher wanted to determine the extent to which themes generated did correspond with existing needs; and a level of reflexivity was used both throughout the focus groups themselves and during the analysis process whereby the researcher was aware of the potential for bias and continued to question whether an existing knowledge of unmet needs in cancer was influencing the current situation.

There were challenges in recruitment for this study that may have impacted upon the sample size achieved. While the purpose of the study was to act as a pilot study and a piece of qualitative research, achieving a sample size that was sufficient for a thorough analysis took longer than initially expected. The challenges of recruiting a variety of haematological cancer diagnoses has already been discussed, there may have also been some systemic issues that compounded the slow recruitment:

- The initial recruitment push was successful but this slowed. Without the continued presence of the researcher in each clinic, momentum may have been lost. In future research, having the researcher present to assist with recruitment may act to reduce clinician burden and maintain a higher rate of recruitment.

- One clinician took the lead on recruiting participants from the hospital. This may have resulted in other clinicians not feeling as though it was their responsibility to approach patients about taking part in the study. In addition, not all of the clinicians were permanent members of staff and the knowledge that they would not be on staff for the duration of the project may have again served to reduce motivation to recruit their patients into the study.

Implications for further work

While this study provides us with a valuable insight into the lived experiences of psychosocial needs in haematological cancer patient, it also highlights the need for quantitative assessment of unmet need in haematology. There is a need for large cohort studies with multiple haematological diagnoses recruited to inform about the unmet needs of different haematological diagnoses to supplement this work on patient experiences. Recommendations by the National Cancer Survivorship Institute (2010) include the use of

cohort studies as a way of mapping areas of need within cancer survivorship and using ongoing research to develop priorities for future studies.

This research suggests a degree of overlap between the needs of haematological cancer patients and previous research conducted with other cancer diagnoses. It is therefore possible that developing a haematology specific add-on for an existing needs assessment tool would be suitable for assessing the needs of this patient group. This has been employed successfully in the assessment of quality of life, the FACT measurement scale has haematology specific modules (Cella et al., 2012), such as the FACT-Leu, that can be used in addition to the FACT general (Cella et al., 1993).

Broadly, the needs discussed by participants can be divided into two group, those that tie in with what we already know about needs in cancer, and those that add something new. With the exception of the themes centred around the specific differences innate to being a haematology patient and the barriers to accessing support; the themes drawn from the focus groups indicate a level of similarity in the type of unmet need found in patients with differing cancer diagnoses. It may be that for some areas of need, for example physical impact, psychological concerns or practical matters, that type of need is common across cancer regardless of the specific diagnosis.

In terms of the implications for clinical practice, the idea that the physical environment in which psychological support is provided is influential to perceptions of acceptability may be an important one. If patients perceive the hospital environment to be one in which physical illness in tended to, then some thought into where this service could be more appropriately placed may serve to make psychological or psychiatric support services more acceptable to general hospital patients. These findings suggest areas of patient need that are directly relevant to both treating clinicians and to wider healthcare services and suggest areas of need that clinicians need to be aware of when interacting with patients and where services as a whole need to consider the current provision of support services for this patient group.

In addition, this work highlights barriers that are preventing patients who would benefit from psychological support from attempting to access this. If HCPs do not raise psychosocial concerns within the clinic, then this research indicates that many patients will not feel able to do so themselves, leaving these needs unaddressed. The need for HCPs to raise concerns and to feel confident in their abilities to do so is key. Existing research

highlights the fact that may HCPs feel a lack of confidence in their ability to manage psychological distress (Moorey, 2013), as such there has been an influx of training programmes that aim to improve confidence and efficacy. Evaluations of these programmes have found that they do improve confidence but it is unclear as to whether there are also improvements in clinician ability to accurately detect distress and whether patient experiences are ultimately improved. There was also an uncertainty from participants about whether existing services for cancer patients were available to haematology patients. It is as yet unclear how HCPs and support staff outside of the haematology setting perceive this patient group and whether they feel them to fall under the more general label of 'cancer patient'.

Conclusion

This work highlights that patients with a haematological malignancy have unmet psychosocial needs that rank alongside patients with other cancer diagnoses, yet participants reported feeling that the level of support available to them was reduced and that understanding of this diagnosis was limited. It was highlighted that unmet psychosocial needs were prevalent within this sample yet barriers to needs being met were identified. Psychological need was identified across the sample yet this is a need that patients find difficult to address with clinicians and can therefore remain unmet. Psychosocial need research in patients with a haematological diagnosis is comparatively sparse. As a qualitative study with a small sample size, results highlight some of the key areas of need as identified by patients and clearly demonstrate a need for further research in this area to build upon the findings presented here. However, it should be noted that, as a piece of preparatory work, the purpose of this study was hypothesis generation, not hypothesis testing. The important questions arising from this piece of work are addressed in the rest of this thesis where empirical quantitative work tracks the type, prevalence and severity of unmet need over time in haematological cancer patients and seeks to investigate the implications of need on psychological wellbeing.

Chapter 4 - The Unmet Psychosocial Needs of Haematological Cancer Patients and their Relationship with Psychological Outcomes

Introduction

Unmet psychosocial needs are thought to be directly related to the level of distress that a person might experience upon learning that they have a diagnosis of cancer, a concept that was discussed in Chapter 2 (Carlson, Waller, & Mitchell, 2012). Previous researchers have postulated a direct link between unmet need and distress, equating the level of psychosocial need with degrees of concurrent emotional or psychological distress (Hall et al., 2014; McIllmurray et al., 2001; Armes et al., 2009). It is, therefore, possible that the level of unmet psychosocial needs at the time of diagnosis may predict broader psychosocial wellbeing in response to a diagnosis of haematological cancer. Prior work in earlier chapters of this thesis has provided an indication of the type of unmet needs that may be important to patients with a haematological malignancy and the specific relevance or importance of individual needs to this specific group of patients. The systematic review detailed in Chapter Two highlighted the lack of quantitative assessment of unmet needs within haematological cancer patients and the potential psychological implications of the presence of unmet need are not well explored or defined within the related literature. In Chapter Three, the perceptions of haematological cancer survivors were explored, raising the issue of differences between haematological cancer patients and patients with solid tumours. In addition, this qualitative work identified barriers to patient access of appropriate support services. This study aims to quantitatively identify the unmet psychosocial needs of newly diagnosed haematological cancer patients, with a special emphasis placed on patients diagnosed with chronic, incurable disease, and to explore the relationship between unmet need and psychological wellbeing in this group. Of the papers included within this systematic review outlined in Chapter 2, none focussed specifically on the unmet needs of haematology patients at diagnosis. Understanding what the unmet needs of patients are is the vital first step in the provision of support services that can effectively meet those needs in a manner that is both relevant and acceptable to patients.

The Unmet Needs of Newly Diagnosed Haematological Cancer Patients

A recent report published by the Department of Health (2012) on the quality of life of cancer survivors highlighted that, in comparison to patients with breast, colorectal or prostate cancer, patients with a diagnosis of Non-Hodgkin's lymphoma (NHL) demonstrated comparatively poor psychosocial outcomes. NHL patients displayed worse levels of maintaining their independence, of anxiety, having the biggest problems completing their usual activities, the most difficulties in planning for the future, the most problems with benefits and displayed the highest levels of pain and discomfort. This major report surveyed patients who received their diagnosis a year or more previously, indicating that psychosocial issues continue to affect patients long after their initial diagnosis and often after initial treatment has been completed. While these findings relate to NHL only, and not haematological malignancies as a whole, given the overarching similarities that exist within this group of cancers, it seems likely that this concerning view of wellbeing is generalizable. There is little research that encompasses the spectrum of haematological diagnoses, making further exploration vital to be able to identify their unmet needs.

Research conducted with patients from wider cancer samples indicates that cancer diagnosis is a time of shock and anxiety (e.g. Cain et al., 1983; Stark & House, 2000) that can be one of the most profoundly challenging within the cancer experience (Boehmke & Dickerson, 2006): a sentiment also reflected by the haematological cancer survivors interviewed in the previous chapter when reflecting on this time. The wider literature indicates that the need for information was felt to be relevant by some, yet for others too much information too soon after diagnosis can become overwhelming. The unmet needs most relevant to individual patients will vary (Harrison et al., 2009), yet providing healthcare professionals with an awareness of the commonly occurring areas of need may prove helpful in facilitating conversations about needs that are not conventionally medical in nature.

Haematological cancers can range from the acute and aggressive to the chronic and incurable. They are notable for their specific treatment modalities, often either more intensive than those required for other diagnoses or, in the chronic and incurable cases, no active treatment may be initially required at all. Previous research indicates that the prevalence of anxiety and depression in haematological cancer patients currently attending

treatment centres is approximately 20% (Clinton-McHarg et al., 2014). In cases where active treatment is not delivered and watch and wait the chosen regime, this can be a direct contrast to the general understanding of what happens when a diagnosis of cancer is given and can bring its own distinct set of challenges. Watch and wait is used in the case of indolent disease and denotes the monitoring of disease via routine blood tests, usually undertaken at outpatient haematology appointments at regular intervals, rather than the commencement of active treatment upon diagnosis (Ardeshna et al., 2003). For some patients, their cancer is detected via a routine blood test that was not undertaken with the view to detect cancer and, at the time, the patient would typically be asymptomatic since they were not actively seeking resolution for symptoms relating to their resulting diagnosis. If a patient does present while asymptomatic, and their diagnosis is one of incurable disease, then the literature has implied no clinical benefit of immediate treatment in prolonging life or improving the outlook for that patient (Lowry & Ardenshna, 2012).

Watch and wait might be a suitable treatment option for patients with indolent NHL (although not the more aggressive, curable sub-types), CLL or myeloma. While not uncommon and based on sound evidence that delaying treatment will not adversely affect outcome (Lowry & Ardenshna, 2012), it is thought that being monitored via watch and wait brings with it its own distinct challenges such as the uncertainty of living with transient symptoms and not knowing when the disease will worsen (Bailey et al., 2004). Watch and wait, sardonically referred to as 'wait and wait' or 'watch and worry' within the online patient community (McCabe, 2014), can bring with it considerable stress and anxiety as patients live with the knowledge that they will, at some unknown time point, become ill. This can create a sense of on-going uncertainty for a patient who may become unsure or unable to form future plans, or for whom the worry about what symptoms may be like once they arise may overshadow other life events, the concern that once their illness is treated, it will be too late is also a very real fear for many patients.

The acute, aggressive cancers requiring intensive treatments have received more attention within the literature building up a more comprehensive understanding of some of the psychological challenges that accompany such a diagnosis and treatment path, notably the psychological impact of bone marrow and stem cell transplantation (Norkin, Hsu & Wingard, 2012). Less is known about the specific issues that arise for patients who are given a life changing diagnosis of cancer and then told that they will not be receiving any treatment for the immediate future.

Adjusting to a Diagnosis of Cancer

The emotional and psychological reaction to cancer diagnosis is central to how a patient experiences their illness. Many are able to cope and to re-adjust, finding a new sense of normality (Costanzo et al., 2007). Others, however, are unable to utilise ways of coping that allow them to manage their emotional and psychological distress. The varying phases of living with and being treated for cancer mean that, for many, adjustment is an on-going process that evolves throughout the initial diagnosis period through to treatment, completing remission, learning that your cancer has relapsed and becoming a cancer survivor.

Adjustment is a term that is often used within psycho-oncology yet the underpinnings of the psychological process are not yet fully understood (Brennan, 2001). Psychological adjustment refers to the process of change that an individual may experience in their view of both themselves and their world. This process is not innately either positive or negative but rather is individual to each person who experiences cancer (Brennan, 2001). There are multiple theories of coping and, as a topic, it has received a huge amount of attention within the literature. One model which has received considerable attention within the field of health psychology has been Lazarus' Transactional Model of Stress and Coping (Lazarus & Cohen, 1977). This model acts as a framework for the processes involved in how people cope with stressful events and situations, citing stressful situations as a transaction between person and environment. The way in which a person reacts to the stressful events depends both upon how they appraise the event and their perceptions of the resources available to them to assist in managing the event (Lazarus & Cohen, 1977). In essence, in the face of a stressful event, two appraisals take place. The primary appraisal involves the person's perception of an event or situation; the secondary appraisal is when the person assesses their own resources and options. The resulting coping efforts are the means by which the person attempts to resolve or regulate the stressor. This model has been repeatedly applied within health psychology research (e.g. Laubmeier et al., 2004; Quine & Pahl, 1991; Shaw, 2001) and can provide a rationale for why some people are better able to cope with stressful events, in this instance the diagnosis of cancer, better than others when in similar situations. Coping is not a fixed attribute, rather it is the innate ability to adapt and employ suitable cognitive or behavioural processes to reduce, avoid or prevent distress (Lazarus, 1992). As a process, it is individual to each moment or situation and involves appraisals and responses in the context of a person's perceived resources

(Lazarus, 1999). Coping in response to stress can be conceptualised as being as much to do with our innate responses to stress, our own personal reactions, as with the situation that is acting as the cause of stress.

Within the psycho-oncology literature, Lazarus' model has been utilised as a framework to determine coping responses and strategies in the context of cancer diagnosis. It has been found that cancer patient's levels of stress is negatively correlated with the presence of both problem-focussed coping and emotion-focussed coping (Kim et al., 2002), that is people are less likely to employ effective methods of coping when stressed. It has also been demonstrated that patients find optimistic, supportive coping strategies to be the most useful (Halstead & Fernsler, 1994) and in breast cancer patients, coping mechanisms have been suggested to mediate the relationship between optimism and distress (Carver et al., 1993). Better understanding of how coping responses influence emotional wellbeing and the factors that affect successful coping in the context of a significant negative event, such as cancer, enables connections to be made between people's coping styles and their emotional wellbeing (Hulbert-Williams et al., 2013).

Previously, adjustment has been thought of as an end goal – to be 'adjusted' as being a state that patients will reach if they are to return to normality and a healthy psychological state of mind. Brennan (2001) argued that instead, adjustment is a process of change and something that is constantly evolving throughout the cancer experience. Patients typically do not report returning to 'normal' after recovering from cancer but rather they create a new sense of normal that accommodates their illness experiences, a potentially difficult adjustment to make (Schnipper, 2003). Watson and colleagues (1998) defined adjustment in the context of the cognitive and behavioural changes that a patient makes in response to their diagnosis of cancer. While this has been criticised for being 'featureless' (Brennan, 2001), this definition does allow for individuality in the way in which patients adjust and does not place any positive or negative connotations on the patient. The Mental Adjustment to Cancer Scale (MAC), and the subsequent Mini-MAC are tools that were developed to assess a patient's psychological adjustment (Watson et al., 1988). Though these specific tools have received some criticism (Hulbert-Williams et al., 2012), understanding the process of adjustment and the factors that might feed into poor adjustment is an important question in psycho-oncology.

There are multiple factors that are thought to feed into how successfully an individual adjusts and is able to cope with a diagnosis of cancer (Watson et al., 1998; Stanton et al., 2002). Research conducted with women with a diagnosis of breast cancer indicated that the presence of hope and faith, with mixed support for approach-oriented coping strategies also being helpful in the adjustment process during the first year post diagnosis (Stanton et al., 2002). The way in which patients appraise their ability to manage both internal and external demands is integral to their ability to cope with a situation. Lazarus and Folkman (1984) define coping as the process of managing these demands. Traditionally, coping theorists, and therefore their perspective on adjustment, have focussed on the behavioural strategies that people might employ in order to manage a potentially stressful situation.

Uncertainty literature

Successful adjustment to a cancer diagnosis can be particularly difficult when a sense of uncertainty is present, as is often the case for haematological cancer patients monitored via a watch and wait regime. Uncertainty as a psychological concept can be defined as the inability to determine the meaning of illness-related events, occurring when the person is unable to assign meaning or to accurately predict the likely outcome (Mishel, 1988). Mishel's Uncertainty in Illness Theory was the first to focus on uncertainty in the context of illness, although work relating to uncertainty more generally goes back much further (e.g. Davis, 1960). The theory is comprised of three key components: antecedents, appraisals, and coping (Mishel, 1988) and proposes a model for how patients develop a sense of uncertainty during illness and their propensity to deal with their uncertainty (Mishel, 2006). Existing research relating to uncertainty in illness has found that uncertainty peaks in the period before diagnosis before decreasing over time but can be reignited by a recurrence. Unpredictability, or an exacerbation of symptoms, can result in increased uncertainty (Mishel, 2006). There may be differences in uncertainty experienced in acute and chronic illnesses, an interesting concept in light of the highly variable prognoses and treatment options that exist under the umbrella term of haematological cancer.

Uncertainty may be a key concern for patients who are monitored via watch and wait: there will be uncertainty related to symptom development; if, and when, treatment will be needed; what form such treatment will take; and, the potential impact of progressing disease. Illness uncertainty can be thought of as a cognitive stressor (Johnson Wright et al., 2009) and only when appraised as a threat does it have a negative impact on wellbeing. In

the context of chronic illness, uncertainty has been found to correspond with psychological wellbeing (Landis, 1996), meaning that illnesses where uncertainty is likely to be raised have an increased potential to impact negatively upon psychological wellbeing. The psychological impact of receiving a diagnosis of cancer and then not receiving any treatment has not been fully explored. It is possible that, due to the lack of physical impact resulting from aggressive disease and intensive treatments, watch and wait patients will have fewer needs and a better overall quality of life (Levin, Li, Riskind, & Rai, 2007; Holzner et al., 2004). Conversely, it could be that by removing the potential to treat, or fight, their disease, a degree of hope is also lost as patients are unable to see an end to their illness or predict the future impact of worsening disease and subsequent treatment while knowing that both are likely to happen within the near future. More research is needed that further examines type of need and psychological wellbeing in haematological cancer watch and wait patients and looks at the impact of not being actively treated for a cancer diagnosis.

Unmet Needs and Psychological Wellbeing

The connection between unmet need and psychological wellbeing has received some attention within the psycho-oncology literature but has yet to be fully defined or examined within haematological cancer patients. It is becoming increasingly well recognised that unmet needs are a key concern for cancer patients: a large multi-centre UK study that included NHL patients found that 30% of patients had five or more unmet needs at the end of treatment, with no improvement six months later for 60% of those patients (Armes et al., 2009). Within Armes' study, fear of recurrence, already highlighted as a key issue for patients within this thesis, was found to predict the presence of unmet need. Baseline mood however, as assessed by the HADS, was not found to be predictive of need. This work by Armes et al highlights the link between needs and outcomes, yet the percentage of NHL patients within this study was comparatively small at just 5%, and no other haematological diagnoses beyond NHL were included within the sample. A further study to explore whether clinical and demographic characteristics relate to the presence of need found gender and age differences in the reporting of need with women reporting more unmet needs on average than men, and younger participants expressing higher numbers of unmet needs (Morrison et al., 2012). Again, while participants with haematological cancers were included within this sample, in total they accounted for approximately 7% of the sample making it difficult to tease out any key differences in the needs expressed by these patients.

In wider cancer groups, the specific relationship between unmet need and distress has been better explored. In breast cancer patients, it has been demonstrated that there is a strong correlation between unmet need and distress (Uchida et al., 2011) and that anxiety is significantly associated with the presence of unmet needs (von Heymann-Horan et al., 2013). Further research within a general oncology sample has indicated that the number of psychosocial problems is correlated with the HADS anxiety score (Schofield et al., 2012; Armes et al, 2009). In palliative care, unmet needs have also been associated with quality of life, anxiety and depression levels (Buzgova et al., 2014). The existing evidence-base linking need with psychological outcomes is small but where previous research has aimed to correlate unmet need with psychological wellbeing, the findings have consistently indicated that there is a relationship present. However, this relationship has yet to be explored within a haematological sample, a group of cancers that are notable in their differences from solid tumours. If found to be present, the connection between unmet need and psychological wellbeing has implications for both the use of needs assessment within the clinical setting to be expanded upon and for the provision of support services within the cancer setting.

Study Aims

This research study aimed to answer thesis question three:

What are the unmet psychosocial needs and psychological outcomes of newly diagnosed patients and are these two concepts related?

Specific study objectives were:

1. To identify the unmet needs of newly diagnosed haematological cancer patients.
2. To investigate psychological wellbeing in newly diagnosed haematological cancer patients.
3. To examine potential differences in need and wellbeing between patients who receive active treatment and those who are monitored via watch and wait; between genders; and between diagnostic groups.
4. To investigate the relationship between unmet need and psychological wellbeing with the hypothesis that higher levels of unmet need will result in poorer psychological wellbeing i.e. that as unmet need increases, so too does anxiety and depression while quality of life will decrease.

Methodology

Study Design

A longitudinal, questionnaire design was utilised. Participants were assessed for unmet psychosocial needs alongside other psychometric assessments at the point of diagnosis (or as close to this time point as is possible) and then again at a three months follow-up.

Sample

The initial aim of this study was to recruit a sample of approximately 211 participants from hospitals across Cheshire, Merseyside, Manchester and later North Wales. All participants were required to have a diagnosis of either: chronic lymphocytic leukaemia (CLL), Non-Hodgkin's lymphoma (NHL) or multiple myeloma (MM) and be within three months of diagnosis. The sample size was determined using GPower and an expectation, based on previous literature, of medium effect sizes (Coe, 2002; Cohen, 1988), power at 0.8 and the potential for up to 39 variables to be included within the analysis. The calculation was based upon the assumption that a regression analysis would be conducted on all data collected. A power analysis was also completed for additional analysis performed, a one-way ANOVA, which indicated a required sample of 159.

Recruitment was discussed with the clinical teams at participating hospitals during protocol development. All teams indicated that the numbers indicated in the power analysis would be possible to achieve during the intended recruitment window of 12 months.

Inclusion Criteria

To be included in this study, patients were required to:

- have a diagnosis of either: CLL, NHL or MM;
- have been diagnosed within the last three months;
- be a patient of either the Countess of Chester Hospital, Royal Liverpool University Hospital or Manchester Royal Infirmary; and
- be able to give informed consent.

Exclusion Criteria

- Anyone with a life expectancy of less than three months.
- Those with severe developmental, learning or psychiatric conditions which may impair their understanding of the research and result in an inability to provide informed consent.

The demographic information of the recruited participants is included in Table 4.1.

Table 4.1: Participant demographic information

Demographic		Percentage
Gender	Male	71.4%
	Female	28.6%
Age	18-30	5.7%
	31-40	5.7%
	41-50	11.4%
	51-60	11.4%
	61-70	31.4%
	71-80	28.6%
	81-90	5.7%
Ethnicity	White	94.3%
	Black/African	2.9%
	Other	2.9%
Employment	Full-time	28.6%
	Part-time	2.9%
	Self-Employed	8.6%
	Retired	48.6%
	Not employed (ill health)	11.4%
Dependents	0	65.7%
	1	8.6%
	2	20%
	3	5.8%
Diagnosis	NHL	45.7%
	CLL	22.9%
	Myeloma	31.4%
Treatment	Active Treatment	68.6%
	Watch and Wait	31.4%

Procedure

Ethical approval was given by the University of Chester Departmental Ethics Committee, the NHS Research Ethics Committee (NREC) and research governance approvals were provided by each participating site.

Recruitment was conducted in collaboration with the clinical team based in each of the participating hospitals. Initially, three hospitals took part in the study: Countess of Chester Hospital, Royal Liverpool University Hospital and Manchester Royal Infirmary with the later addition of the North Wales Cancer Treatment Centre. Inclusion criteria were assessed by the member of the clinical team within each hospital and verified with the researcher. If it was deemed appropriate, the clinician conducting the appointment introduced the basic premise of the study to participants. If participants were interested in learning more about the study, their clinician introduced them to the researcher who was available during clinic sessions to answer queries and to provide information packs.

Participants who were interested in taking part in the study were provided with an information pack to take home with them containing an information sheet about the study and what taking part would involve (Appendix 14) and a consent form (Appendix 15). Information packs were also available from clinicians if required. If patients wished to take part, they returned the participant consent form to the researcher.

Where patients decided to participate, they were required to complete a questionnaire (Appendix 17) on two separate occasions: once when they were first recruited into the study around the time of receiving their diagnosis; and again at a three-month follow up. Along with the questionnaire, participants were provided with a debrief sheet (Appendix 16) including contact details for appropriate support services. This was posted out along with the questionnaire to ensure that participants had access to the information contained within as it might be needed.

Upon recruitment into the study, letters were sent to the participant's GP to inform them of their patient's involvement in the study (Appendix 17). To facilitate this, participants were asked to provide details of their GP on the questionnaire. One week prior to follow up, a form was sent to the GP that was to be returned if a participant is no longer eligible to take part in the study (Appendix 18) and confirmed with the hospital. Patients were defined as no longer eligible to take part if they were not expected to live longer than two weeks, if they were too ill to take part or if they were known to have died.

Unfortunately, retention into the study was poor and only eight follow up questionnaires were received. In light of the revised study aims and the removal of the analysis that had been intended to examine predictors, the decision was made to exclude this data from the

study, focussing instead on the cross-sectional data relating to the psychological impact of diagnosis.

Informed Consent, Confidentiality and Data Protection

Prior to completing the questionnaire, participants were requested to read the full information sheet and to contact the research team to ask any questions that they may have before deciding whether or not they wished to take part in the study. Participants were given the opportunity to discuss the study with the researcher or with a member of their clinical team if they had any questions.

To protect patient confidentiality, no questionnaire contained patient identifying information; rather each was labelled with an identification number that corresponded to the number assigned to the participant consent form. Clinical data and socio-demographic data, as reported in Table 2 previously, was self-reported by participants and confirmed with the medical team if missing.

All returned questionnaires were stored in a locked cabinet in a secure storage room at the University of Chester. In accordance with the Caldicott Principles, all information was held on a strictly need to know basis. All electronic data was stored on a password protected area on a server at the University of Chester and accessed by BS only with NHW to be allowed access in case of emergency. All data analysis was conducted on university computers. Long-term storage of all documents was in University of Chester secure archives.

Measures

The questionnaire included the following psychometrically valid and reliable measures (Appendix 17):

- Unmet psychosocial needs: SCNS-SF34 (Bonevski et al., 2000). The SCNS SF34 is a 34 item measure designed to assess the unmet needs of adult cancer patients. Need is measured on a likert scale from 1 (no need) to 5 (high need). Domains are as follows: physical and daily living (PDL); psychological (psych); health systems and information (HSI); patient care and support (PCS); and sexual. This measure was chosen over other needs assessment tools due to its wide usage within cancer

research as evidenced by the systematic review (Chapter 2) and the fact that is was designed to assess generic needs within cancer patients.

- Anxiety and depression: Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). The HADS is a 14 item measure designed to assess levels of anxiety and depression. Answers are ranked from 0-3 for each item. The measure has two sub-domains: anxiety and depression, each with seven items. This measure was chosen due to its wide usage both within cancer research but within the wider health psychology field as evidenced within the literature reviews included within this thesis.

- Quality of life: EORTC QLQ-C30 (Aaronson et al., 1993). This is a 30 item QoL tool where items are ranked from 1 (not at all) to 4 (very much). There are nine sub-scales: five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, and nausea and vomiting); and a global health and quality-of-life scale. This measure was chosen due to its common usage within the studies included within the systematic review in Chapter 2 and the fact that it was designed to assess QoL within cancer specifically. While the FACT QoL measure does have both leukaemia and lymphoma specific scales, having different scales in use within the same study was felt to reduce opportunities to draw direct comparisons from across the whole sample. In addition, the EORTC QLQ-C30 was more widely used in the previous literature as highlighted previously, enabling comparisons between this sample and others.

- Social Distress: SDI-21 (Wright et al., 2008). A measure of social distress rating items from 0 (no difficulty) to 3 (very much difficulty). The measure covers a range of everyday difficulties experienced by cancer patients (independence, domestic chores, personal care, care of dependents, support for dependents, welfare benefits, finances, financial services, work, planning the future, communication with those close to you and others, plans to have a family, sexual matters, body image, isolation, mobility, where you live, recreation and holidays). Questions ask responders about their difficulty levels, ranging from “No difficulty” to “Very much”. This scale was included within the questionnaire in order to address social wellbeing in addition to the psychological assessments.

- Benefit Finding: Benefit Finding (Carver & Antoni, 2004). A 17 item measure originally developed for use in breast cancer patients. Items measured responses from 1 (not at all) to 5 (extremely). Although developed for use in breast cancer patients, it was felt that this was the most well validated measure of benefit finding in cancer populations. The content of the questionnaire and the scoring system was not altered in any way with the exception of the initial question that leads into the questionnaire, "Having had breast cancer…" being amended to "Having had cancer…".

- Demographic questionnaire. This assessed demographic variables: age, gender, ethnicity, employment, dependents, diagnosis, and treatment.

For each measure, Cronbach's Alpha, a measure of internal consistency or how closely related a group of items are, was conducted. As summarised in table 4.2, all measures included within the questionnaire have a Cronbach's Alpha of above 0.7 which indicates an acceptable level of internal consistency (Bland & Altman, 1997), the generally accepted level at which a measure is deemed suitable for use within a sample.

Table 4.2: Cronbach's Alpha for measures included within study questionnaire

Measure	Cronbach's Alpha
HADS A	0.75
HADS D	0.87
SCNS SF34	0.97
EORTC QLQ-C30	0.90
MiniMAC	0.91
BriefCOPE	0.85
Benefit Finding	0.94
SDI-21	0.87

Procedure Should a Questionnaire Indicate Clinically Significant Levels of Risk

Immediately on return of questionnaires, responses to the HADS were read as a proxy screen for clinically significant levels of distress (defined as 11 or more on either the anxiety or depression sub-scales of the HADS as defined on the HADS scoring sheet (Zigmond & Snaith, 1983)). Where the participant had agreed on the consent form for the researcher

to do so, the researcher then approached the treating clinician for these individual patients to discuss an appropriate referral to support services within the participant's treating hospital. Of the 35 participants that returned the questionnaires, three met clinical cut offs for anxiety, two also for depression (defined as a score of more than 10 on the HADS). In two cases the patient was then contacted by their clinical team for an informal conversation about how they were. In neither of these cases did the patient indicate to their clinician that they felt that they required additional support. This corresponds with previous findings that state that only a minority of cancer patients with depression want formal support for this (Baker-Glenn et al., 2010). In the case of the third participant to meet clinical standards for distress, it was stated that psychology input had already been offered but had been declined. As such, no further immediate action was taken by the hospital.

Data Analysis

Data analysis consisted of three stages in line with study hypotheses: descriptive statistics and exploratory analysis of whether data met parametric assumptions; sub-group comparisons (objective 3); and correlation between variables (objective 4). The original analysis plan for the study was to also run a multiple regression in order to examine predictor variables for later psychological outcomes (objective 4): due to the smaller than anticipated sample size however, this part of the analysis was not run due to lack of power.

Response Rates

After 14 months of recruitment, only 35 participants had been recruited into the study despite the researcher typically attending four clinic sessions per week. This was clearly substantially below the intended sample size but recruitment into the study had to close for practical reasons. Before moving on to discuss the rest of this study, a short discussion of recruitment issues and actions taken in an attempt to improve recruitment follows.

Advice received from our clinical collaborators in the preparation of the study indicated that it would be feasible to recruit 200 patients from 3 hospital sites given the geographical range of the three hospitals in question and their populations served. Once it was clear that this would not be achieved a number of steps were taken to assess the accuracy of this information, and a number of minor methodological adjustments were made to

recruitment processes in an attempt to boost both numbers recruited into the study and response rates for the questionnaire.

Records from the Somerset database of cancer diagnoses (anonymised) were subsequently analysed once the study was underway and research access had been granted. These indicated that there were close to 200 diagnoses within the included clinical sites and the planned recruitment time period, but that this figure did not take into account patients who were excluded from this study, for example: those who had relapsed as opposed to been given a new diagnosis; those who did not meet eligibility criteria for another reason (e.g. capacity); those who were deemed unsuitable to take part (e.g. known high distress, family problems, history of complaints); those who were immediately transferred elsewhere and did not remain a patient within the hospital; those who died soon after diagnosis; and a small number that were missed during the recruitment process. Initial clinical estimates made by clinical collaborators on the study were substantial overestimates of actual figures. Thus, a decision was made to introduce a fourth recruitment site into the study (North Wales Cancer Treatment Centre). This was a large enough geographical catchment area to boost numbers while still ensuring that the researcher would continue to be able to attend clinics in person to encourage recruitment that way. The rural setting of the hospital was also felt to provide contrast with the city centre hospitals already participating in the study.

According to Somerset Records, even once ineligible patients were deducted, and even with the additional fourth site included, the number of eligible patients numbered only 110 over the recruitment period. It remains unclear why the initial estimates from the clinicians were so radically out of proportion to the reality of diagnosis and this was a significant issue in conducting this study.

A national report more recently published on the incidence of haematological malignancies demonstrated that between 2006 and 2008, 8718 patients were diagnosed with CLL, NHL or myeloma in England (NCIN, 2013). There are 168 acute hospital trusts in England. While there will be differences in the number of patients diagnosed between trusts, as a scoping exercise, if the total number of diagnoses is divided by the number of trusts in England, there will have been approximately 52 diagnoses per trust within that two year period. As

recruitment took place across four sites, this would have made an approximate total number of diagnoses for the included sites at 208 for the period between 2006-2008.

Other strategies to maximise recruitment involved the researcher, whilst in clinic (at each site, on either a weekly or bi-weekly basis) spending time with the Clinical Nurse Specialist in charge of that clinic to ensure that the list of patients attending that clinic were reviewed in full and all eligible patients identified. Whilst this did not seem to improve recruitment, it did ensure that recruitment practice at each site was of a high standard and that study referral was not biased. Where patients were identified as eligible and agreed to receive the study information pack, efforts were made to ensure that the researcher could meet with the patient in person to explain the study and to answer any questions. Not only is this ethically-minded but also has been demonstrated to improve response rates (Galea & Tracy, 2007).

Finally, part way through the recruitment window, the questionnaire was made more user friendly. In line with recommendations from previous research, the questionnaire was printed on green paper (Fox et al., 1988) and formatted using Microsoft Word rather than the initial use of the Formic Software to make the design more user friendly (Dillman, 1993). Names and addresses were handwritten on each questionnaire and envelope (Fox et al., 1998), again thought to improve response rates by making the questionnaire seem more personal.

Analysis of eligibility and recruitment rates at the end of the study demonstrated that of the 110 patients diagnosed, approximately 30 immediately declined to take part in the study (no records were kept, unfortunately, regarding who these patients were). 71 patients provided verbal consent to receive a questionnaire pack, of which 35 (50%) were returned. This is in line with expected response rates for studies of this type (Armes et al., 2009; Hawkins et al., 2008; McDowell et al., 2010) but to have achieve the initial target sample size would have need recruitment over a much longer period, or across more clinical sites, neither of which was feasible within the constraints of this project.

In light of the recruitment difficulties experienced, the aims of the study were readjusted and the analysis plan simplified. The original intent was to determine whether unmet needs predicted psychological outcomes using a multiple regression technique. This was

amended to correlations to determine the presence of the relationship with additional testing used to explore differences between groups. Given the lack of existing literature relating to the unmet needs of newly diagnosed haematological cancer patients, even this smaller, more exploratory study fills a gap in the literature and makes a useful contribution to knowledge.

The revised analysis plan consisted of descriptive statistics being run for each measure for the sample as a whole including means, medians, percentages and standard deviations calculated as appropriate to describe the sample. Comparisons between subgroups on demographic, treatment and disease variables (e.g. gender, diagnosis, treatment modalities received) were carried out using t tests and analysis of variance for normally distributed continuous variables. Correlations between unmet need and outcomes were conducted using Pearson's product-moment correlation coefficient.

Examination of both graphical displays (e.g. scatter plots, histograms, Q-Q plots) of the dataset and running Kolmogorov-Smirnov tests for the key variables that were to be included within the analysis (Table 4.3) determined that the data was normally distributed and that there was a linear relationship. Type of data was also suitable with outliers also not presenting a problem. There was somewhat of a floor effect present on the unmet need scale (SCNS) due to a high number of participants selecting the 'no need' response; however, given that the remaining key variables were normally distributed and the repeated questioning within the related literature with regards to the need for parametric conditions to be met (Bryman & Cramer, 2011; Games & Lucas, 1966), the decision was made to use parametric testing.

Table 4.3: Kolmogorov Smirnov Tests of Normality for Study Measures

	Kolmogorov-Smirnov[a]		
	Statistic	df	Sig.
HADS Anxiety	.158	25	.106
HADS Depression	.118	25	.200
EORTC Global score	.115	25	.200
SD_16	.143	25	.200
SDI Single items	.109	25	.200
BriefCOPE	.074	25	.200
Benefit Finding	.131	25	.200
SCNS Total	.219	25	.003

Results

Participants completed questionnaires that assessed their unmet psychosocial needs, their anxiety and depression levels, quality of life, social distress, benefit finding and coping. Means and standard deviations for each of these key outcomes for the sample as a whole are presented in Table 4:

Table 4.4: Means and standard deviations for key measures.

Measure	Mean (S.D.)
Anxiety (HADS)	5.97 (4.33)
Depression (HADS)	4.41 (3.48)
Quality of Life (EORTC QLQ-C30)	4.91(1.40)
Unmet Needs (SCNS SF34)	67.5 (28.14)
Social Distress (SDI-21)	12.3 (11.2)
Benefit Finding	3.01 (0.99)

Objective 1: Unmet Need in Newly Diagnosed Haematological Cancer Patients

The first study objective was to identify the unmet needs of newly diagnosed haematological cancer patients. There were a range in the number of unmet needs reported across the sample. For each individual item included on the SCNS SF34, there was unmet need reported within the sample.

Thirty one out of 35 participants (89%) reported at least one unmet need on the SCNS SF34 while 19 (54%) reported five or more unmet needs. 13 participants (37%) reported the presence of one or more high unmet need and four participants (11%) reported five or more high unmet needs.

The five most highly rated unmet needs across the sample were:

1. Concerns about the worries of those close to you (51.4%)
2. Not being able to do the things you used to (50%),
3. Uncertainty about the future (44.1%),
4. Lack of energy/tiredness (42.9%),
5. Learning to feel in control of your situation (40%).

Objective 2: The Psychological Wellbeing of Newly Diagnosed Haematological Cancer Patients

Study objective two was to determine the psychological wellbeing of newly diagnosed haematological cancer patients.

These data indicate that, as a sample, distress rates are below the clinically significant range. Looking in more detail at scatter plots of key outcomes in Figures 4.1-4.3, we can see that the majority of participants have low levels of anxiety and depression but that quality of life is more varied within the sample.

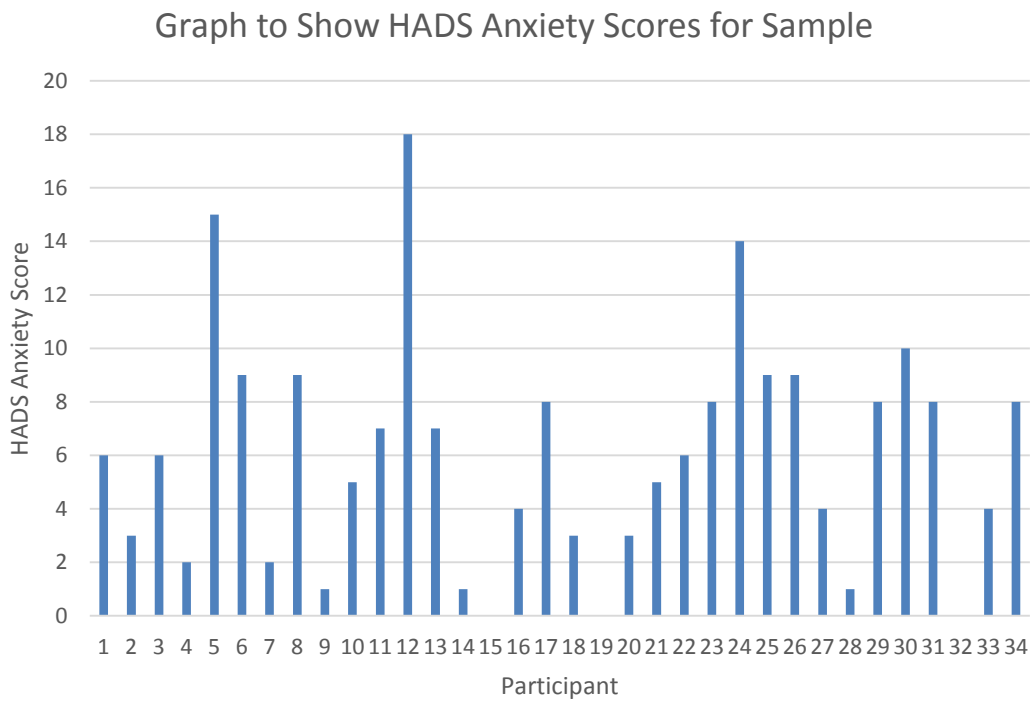

Figure 4.1: Bar chart to illustrate the spread of anxiety score.

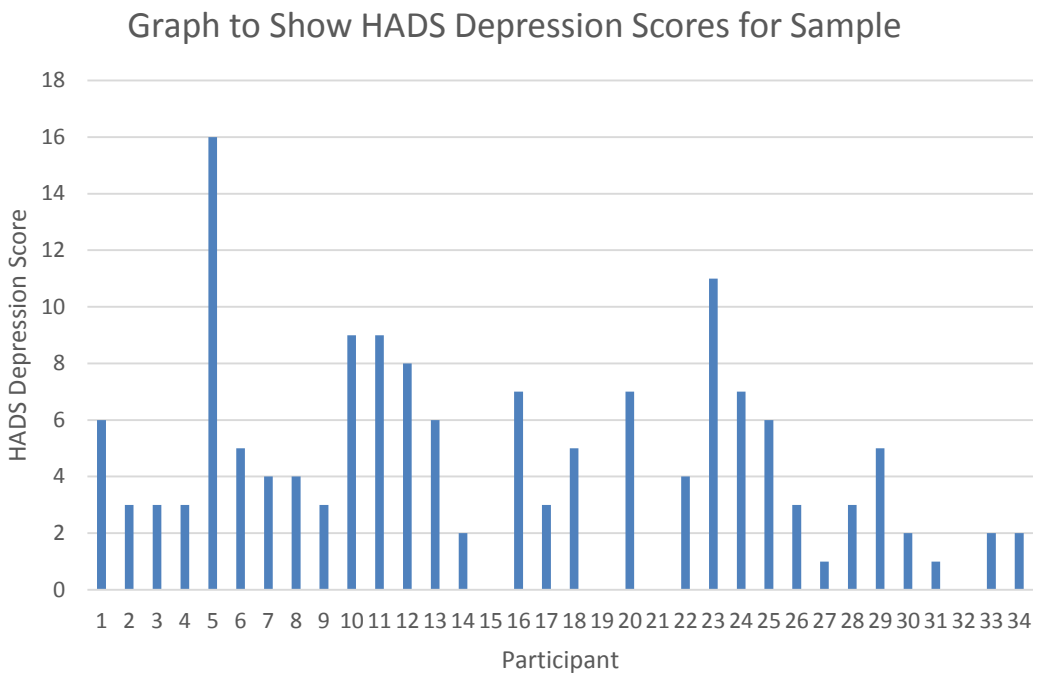

Figure 4.2: Bar chart to show to spread of depression scores within the sample.

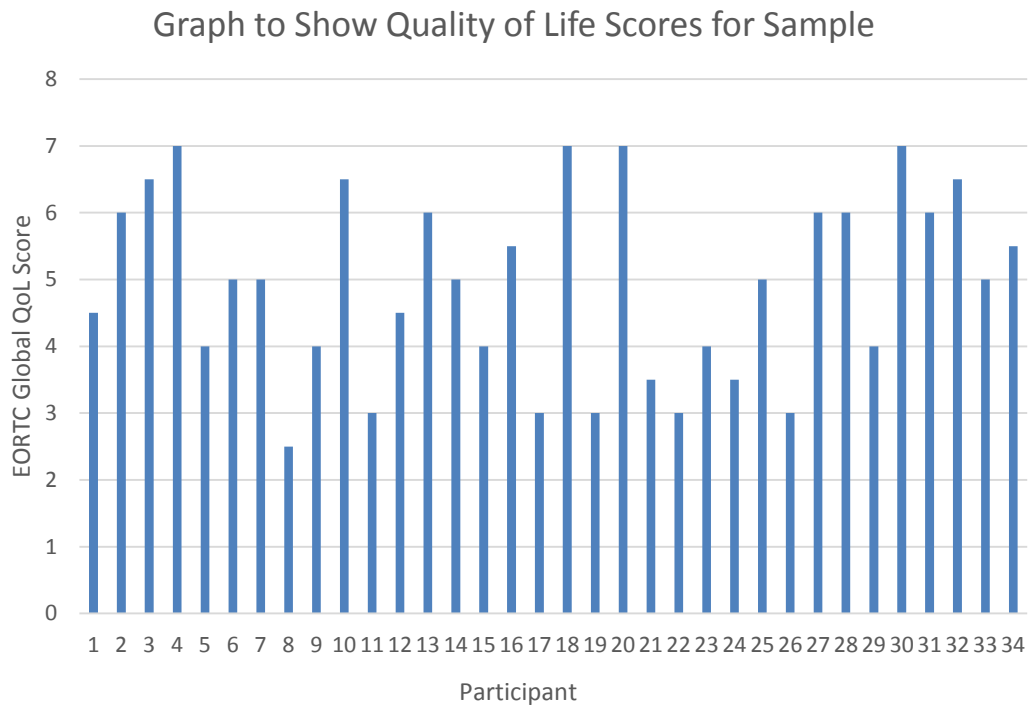

Figure 4.3: Bar chart to show the spread of QoL scores within the sample.

The spread of data for each of these outcome measures indicates that distress is prevalent within only a minority of the sample.

For anxiety, three out of 34 participants (8.8%) fell within the clinically significant range. A further 10 participants (29.4%) fell within the borderline clinically significant range for anxiety (defined as a score of 8-10 on the HADS). In total, 38.2% of participants reported anxiety levels at borderline clinically significant levels or above. For depression, two out of 34 (5.9%) fell within the clinically significant range. A further three participants (8.8%) had scores that fell within the borderline clinically significant range. In total, 14.7% of participants reported levels of depression at a borderline clinically significant level or above.

Objective 3: Sample Differences in Need and Distress

The third study objective was to investigate differences within the sample, placing an emphasis on the differences between diagnoses, gender and treatment modalities.

Diagnostic Groups

Three different haematological cancer diagnoses were included within the sample: NHL (45.7%), CLL (22.9%) and myeloma (31.4%).

Table 4.5: Mean scores and standard deviations for key outcomes for each diagnostic group.

	NHL	**CLL**	**Myeloma**
Unmet Need (SCNS SF34)	77.38 (34.28)	52.25 (18.51)	63.8 (16.84)
Anxiety (HADS)	7.75 (4.84)	3.64 (3.58)	5.00 (2.87)
Depression (HADS)	4.94 (3.61)	2.25 (3.01)	5.30 (3.20)
Quality of Life (EORTC QLQ-C30)	4.59 (1.23)	6.62 (0.44)	4.05 (0.93)

Table 4.5 indicates that participants with a diagnosis of NHL had both highest levels of unmet need and highest distress. Participants with CLL had the lowest levels of distress and the highest QoL.

Performing a One-Way ANOVA to explore differences between the three groups indicated that there was a statistically significant difference between groups for QoL [$F(2,31) = 15.899$, $p = <.001$], although not for the other outcome variables.

Further testing (Tukey HSD) indicated that participants with a diagnosis of CLL were statistically different from participants with either NHL or myeloma. The mean difference between CLL and both NHL and myeloma was significant at $p = <.001$ for both groups. There was no significant difference between participants with NHL and myeloma. Participants with CLL therefore has a significantly better QoL when compared to participants with NHL or myeloma.

Gender

The sample was 71.4% male (N = 24) and 28.6% female (N = 10). Lack of energy/tiredness, uncertainty about the future and concerns about the worries of those close to you were the most highly rated unmet needs among female participants. Lack of energy/tiredness, being informed about test results as soon as is feasible and work around the home were the most highly rated unmet needs by male participants.

Table 4.6 illustrates that both genders were comparatively similar in terms of the levels of distress, unmet need and quality of life. This is supported by the results of t tests conducted for each outcome, no statistically significant gender differences were found. The low number of participants may factor into the lack of statistically significant findings as the low N is likely to correspond to a lack of statistical power.

Table 4.6: Means and standard deviations for key outcomes according to gender.

	Male	**Female**
Unmet Need (SCNS SF34)	66.42 (31.84)	70.00 (17.37)
Anxiety (HADS)	5.21 (4.54)	7.80 (3.29)
Depression (HADS)	4.42 (3.88)	4.40 (2.46)
Quality of Life (EORTC QLQ-C30)	4.81 (1.37)	5.15 (1.51)

Treatment Sub-Groups

68.6% of the sample were currently receiving active treatment, 31.4% had been monitored via watch and wait since diagnosis. Not being able to do the things you used to do, anxiety, concerns about the worries of those close to you, lack of energy/tiredness and uncertainty about the future were the most common unmet needs in participants receiving active treatment. Concerns about the worries of those close to you, fears about the cancer spreading, worry that the results of treatment are beyond your control and being given explanations of those tests for which you would like explanations were the most common unmet needs in watch and wait patients.

Table 4.7 highlights that there are differences in needs, distress and QoL between patients receiving active treatment and those being monitored via watch and wait. Unmet needs, anxiety and depression are lower and QoL higher in watch and wait patients.

On conducting t tests for each of these four outcomes, significant differences were found between groups for depression [$t(32) = 3.31$, $p = .002$], unmet need [$t(32) = 2.56$, $p = .015$] and QoL [$t(32) = -3.70$, $p = .001$]. No significant differences were found for anxiety.

Table 4.7: Means and standard deviations for key outcomes according to treatment sub-group.

	Active Treatment	Watch and Wait
Unmet Need (SCNS SF34)	75.39 (29.1)	50.90 (17.27)
Anxiety (HADS)	6.87 (4.31)	4.09 (3.91)
Depression (HADS)	5.60 (2.63)	1.91 (2.63)
Quality of Life (EORTC QLQ-C30)	4.39 (1.20)	6.00 (1.16)

Objective 4: The Relationship between Unmet Need and Psychological Wellbeing

The fourth objective for the study was to investigate the potential relationship between unmet need and psychological wellbeing in newly diagnosed haematological cancer patients.

Correlation between Variables

A key research question was to determine whether there was a relationship between unmet need and psychological wellbeing. Correlation between variables was examined between unmet needs according to both needs measures used and psychological outcomes.

Table 4.8: Correlation Between Variables

		Anxiety	Depression	QoL	Benefit Finding
SCNS Total Needs	r	.47	.60	-.53	.44
	p	.006	.000	.001	.012
SCNS Physical and Daily Living Needs	r	.17	.33	-.47	.50
	p	.351	.058	.006	.004
SCNS Psychological Needs	r	.60	.49	-.50	.58
	p	.000	.004	.003	.001
SCNS Health Systems and Information Needs	r	.37	.57	-.37	.23
	p	.033	.001	.035	.212
SCNS Patient Care and Support Needs	r	.32	.50	-.44	.15
	p	.063	.002	.010	.403
SCNS Sexual Needs	r	.38	.52	-.52	.32
	p	.027	.002	.002	.069

The correlations cited within Table 4.8 indicate that there is a relationship present between unmet needs and psychosocial outcomes. For needs total score, all relationships were found to be statistically significant. The effect sizes observed in the significant correlations were within the medium-large range. For the correlations between unmet need total score and each of the five measures of wellbeing, two of the effect sizes would be categorised as medium (anxiety and benefit finding) and three as large (depression, QoL and coping). The positive correlation between unmet need and anxiety and depression indicate that where once increases, so does the other, thereby indicating that higher levels of unmet needs correspond with higher levels of anxiety and depression within the sample. The negative correlation between unmet need and QoL means that the opposite is true in this instance, where unmet need increases, QoL decreases (and vice versa). In addition to correlation between total need score, sub-domain scores and outcome variables, correlations between each individual need item on the SCNS SF34 and key outcomes variables anxiety, depression and QoL were performed in order to determine whether any individual need items were particularly strongly correlated with an outcome (Table 4.9).

Table 4.9: Correlation between SCNS SF34 items and key outcome variables.

SCNS SF34 Item		Anxiety	Depression	QoL
Pain	r	.24	.17	-.30
	p	.181	.326	.086
Lack of energytiredness	r	.24	.40	-.49
	p	.177	.020	.003
Feeling unwell a lot of the time	r	.21	.16	-.41
	p	.243	.361	.018
Work around the home	r	-.03	.25	-.19
	p	.852	.147	.281
Not being able to do things you used to do	r	.05	.30	-.48
	p	.789	.091	.005
Anxiety	r	.25	.12	-.39
	p	.163	.506	.024
Feeling down or depressed	r	.44	.17	-.33
	p	.010	.349	.060
Feelings of sadness	r	.41	.11	-.45
	p	.019	.543	.009
Fears about the cancer spreading	r	.35	.08	-.27
	p	.042	.643	.129
Worry that the results of treatment are beyond your control	r	.52	.43	-.27
	p	.002	.011	.130
Uncertainty about the future	r	.63	.63	-.38
	p	.000	.000	.030
Learning to feel in control of your situation	r	.42	.58	-.45
	p	.013	.000	.007
Keeping a positive outlook	r	.53	.50	-.40
	p	.001	.002	.021
Feelings about death and dying	r	.64	.57	-.45
	p	.000	.000	.008
Changes in sexual feelings	r	.25	.49	-.48
	p	.152	.004	.004
Changes in your sexual relationships	r	.36	.56	-.56
	p	.036	.001	.001
Concerns about the worries of those close to you	r	.41	.51	-.47

	p	.015	.002	.005
More choice about which cancer specialists you see	r	.37	.40	-.25
	p	.034	.018	.162
More choice about which hospital you attend	r	.33	.44	-.28
	p	.058	.010	.108
Reassurance by medical staff tha the way you feel is normal	r	.22	.59	-.17
	p	.220	.000	.343
Hospital staff attending promptly to your physical needs	r	.12	.12	-.50
	p	.583	.498	.003
Hospital staff acknowledging and showing sensitivity to your feelings and emotional needs	r	.31	.47	-.55
	p	.074	.005	.001
Being given written information about the important aspects of care	r	.33	.53	-.36
	p	.060	.002	.042
Being given information written diagrams drawings about aspects of managing you illness and sideeffects at home	r	.33	.32	-.45
	p	.061	.067	.008
Being given explanations of those test for which you would like explanations	r	.21	.48	-.17
	p	.239	.004	.326
Being adequately informed about the benefits and sideeffects of treatments before you choose to have them	r	.29	.58	-.23
	p	.093	.000	.197
Being informed about your test results as soon as feasible	r	.32	.51	-.49
	p	.067	.002	.003
Being informed about cancer which is under control or diminishing that is remission	r	.27	.42	-.35
	p	.122	.013	.040
Being informed about things you can do to help yourself to get well	r	.45	.46	-.29
	p	.008	.006	.095
Having access to professional counselling eg psychologist social worker counsellor nurse specialist if you family or friends need it	r	.38	.54	-.26
	p	.029	.001	.142
Being informed about sexual relationships	r	.48	.45	-.43
	p	.004	.008	.012
Being treated like a person not just another case	r	.34	.54	-.35
	p	.052	.001	.045
Being treated in a hospital or clinic that is as physically pleasant as possible	r	.31	.51	-.33
	p	.074	.002	.055
Having one member of staff with whom you can talk to about all aspects of your condition treatment and followup	r	.29	.42	-.24
	p	.093	.013	.175

Seven unmet needs were found to significantly correlate with all three key outcome variables: uncertainty about the future; learning to feel in control of your situation; keeping a positive outlook; feelings about death and dying; concerns about the worries of those close to you; changes in your sexual relationship; and being informed about sexual relationships. All of these needs fall within either the unmet psychological need or unmet sexual need domains on the SCNS SF34. Where correlations between unmet need and outcomes were significant, the effect sizes were all at least medium with many falling within the large range, indicating a strong relationship between the variables.

The decision was made not to include Bonferroni corrections within the analysis. This decision was made based on several factors: Bonferroni corrections have been criticised for being overly conservative which can create liability for a Type II error (Cohen, 1994) and arguments for other testing procedures have been made (Bender & Lange, 1999). In light of both these criticisms and the exploratory nature of this research when combined with the results of the correlation analysis being consistent with both the hypothesis stated under the study aims and the wider literature, Bonferonni corrections were not used.

Discussion

Research relating to the unmet psychosocial needs of haematological cancer patients is scarce in the existing literature, with only three studies identified within the systematic review (Chapter 2). This quantitative study attempted to begin to remedy this by identifying the unmet psychosocial needs of newly diagnosed haematological cancer patients. The study objectives were:

1. To identify the unmet needs of newly diagnosed haematological cancer patients.
2. To investigate psychological wellbeing in newly diagnosed haematological cancer patients.
3. To examine potential differences in need and wellbeing between patients who receive active treatment and those who are monitored via watch and wait; between genders; and between diagnostic groups.
4. To investigate the relationship between unmet need and psychological wellbeing with the hypothesis that higher levels of unmet need will result in poorer psychological wellbeing.

Considerable difficulties were encountered in recruiting the desired numbers of participants in order to fulfil the original analysis plan. In light of these concerns, a number of attempts were made to improve recruitment and ultimately the analysis plan for the study was re-defined to accommodate the revised participant numbers. An additional site was added, attempts were made to boost recruitment in the clinical setting by ensuring that all eligible participants were being approached about taking part in the study in order and by amending the format of the questionnaire in an attempt to make it more user-friendly and boost response rates. The analysis plan was subsequently simplified in an attempt to reduce the effect of a lack of statistical power due to low number of participants, while still meeting the study objectives and obtaining findings that would develop the current knowledge of unmet need in haematological cancer patients.

Difficulties in recruitment may be reflective of there being so few studies identified in the systematic review that relate to need in haematological cancer populations. If recruitment proves to be such a significant challenge, then it may be that researchers focus on the more common cancer groups as quicker, more accessible patient populations to recruit. However, the significant disparities between haematological cancer patients and those

with solid tumours warrant a much more in depth exploration of their psychological wellbeing than is currently present within the research literature. Indeed, the psycho-oncology literature is such that it predominantly relates to a specific sub-group of diseases to the exclusion of others. A full exploration of this issue and the potential impact upon patient wellbeing is undertaken in Chapter 6.

Despite this, a number of novel, important results have been found. Understanding the type of need relevant to a patient group is the crucial first step in being able to efficiently meet these needs within the clinical setting (Watson et al., 2012; Carlson et al., 2012) and to be able to go on to develop effective interventions (Abrahamson, 2010). This study contributes knowledge by identifying the specific unmet needs of haematological cancer samples at the time of diagnosis: both for the sample as a whole and by specific sub-groups that were felt to hold the most clinical utility. The most highly rated unmet needs across the sample were: not being able to do the things you used to; lack of energy/tiredness; and uncertainty about the future. Reviewing the findings from both the systematic review and qualitative study already detailed within this thesis reveal that fear of recurrence, information needs, concerns about the worries of those close to you, keeping positive, having a key worker and fatigue have been the most common unmet needs within these studies with information needs and fear of recurrence being highlighted in both pieces of work. Clear patterns relating to areas of need that have relevance to haematological cancer patients are emerging: uncertainty about the future, including whether or not they are 'cured' from their disease; a need for understandable, relevant information; concerns about those close to you and fatigue (Harrison et al., 2009; Armes et al., 2009; Morrison et al., 2012).

Information needs and needs relating to psychological wellbeing are not uncommon at the point of diagnosis (Puts et al., 2012) with up to 93% of newly diagnosed older cancer patients (mixed clinical sites) identifying as having unmet needs in these areas. A systematic review of the unmet needs of cancer patients highlighted psychological and information needs as being common within cancer patients, but highlighted needs within the activities of daily living domain as being the most frequently reported (Harrison et al., 2009). These needs are different from those identified as most important within both this study and those already discussed in previous chapters, this may be reflective of differences between haematological cancer patients and more general cancer samples. In this study particularly, the inclusion of watch and wait patients who were not yet

undergoing any treatment for their diagnosis may have reduced the importance of physical and daily living needs within the sample due to the absence of cancer treatments known to have physical side-effects.

Anxieties about the future in light of a cancer diagnosis are common with fear of recurrence having an existing body of research dedicated to its understanding (Llewellyn et al., 2003; Rogers et al., 2008; Ozakinci et al., *under review*). A recent review highlighted fear of recurrence as being frequently identified as the major concern for cancer survivors (Simard et al., 2013). In head and neck cancer patients, it has been demonstrated that fear of recurrence is related to the presence of intrusive thoughts and heightened negative emotions (Rogers et al., 2008), unsurprising in light of the finding that unmet needs and psychological wellbeing are related. Work within this thesis has demonstrated that fear of recurrence is also a key concern for haematological cancer patients. The analysis of the correlation between individual items on the SCNS SF34 and psychological wellbeing, found that fears about the cancer spreading correlated with levels of anxiety in the sample. As this is also found in broader cancer diagnoses this speaks to the generalisability of this phenomenon, highlighting the clinical importance.

As a sample, the average distress levels were below clinically significant cut-offs as determined by the HADS. Yet, the results also highlight that there is a significant minority of patients for whom anxiety and depression are present. For anxiety, 38.2% of the sample displayed levels of anxiety at the borderline clinical cut-off or above, with a figure of 14.7% for depression. In comparison, 4.7% of the general population in the UK experience anxiety problems with 2.6% experiencing depression (Swift et al., 2014). This large disparity in prevalence rates for these disorders compared with the general population thus supports the proposition that a diagnosis of cancer directly impacts upon psychological wellbeing in haematological patients.

As is perhaps to be expected, there were differences identified in the most common unmet needs within participant sub-groups, gender included, although differences between genders were not statistically significant. Given previous research that indicates that women are at higher risk of having unmet needs (Hodgkinson, Butow, Hunt, & Wain, 2006), this is perhaps surprising. Observing item by item responses, men appear to rate more practical needs more highly whereas women were more likely to highlight needs relating to their emotional wellbeing. Women highlighting needs connected to psychological or

emotional domains is not a new finding, previous research looking at need in breast cancer samples has highlighted that women with cancer often report unmet needs within the psychological domain (Uchida et al., 2011), and express the need for counsellors to be available to help manage the psychological impact of their illness (Ruddy et al., 2013; von Heymann-Horan et al., 2013).

Patients being monitored via watch and wait were less likely to highlight physical needs than their peers receiving treatment but conversely were more likely to have psychological needs relating to uncertainty and the lack of control they are currently experiencing. This is not surprising finding given the nature of watch and wait; patients are given a diagnosis of cancer yet informed that they will not receive treatment at this time, although their condition is likely to worsen in the future. The concept of uncertainty has been explored in patients with indolent NHL (Elphee, 2008) whereby it was also reflected that the chronic, incurable nature of the disease coupled with the transient, vague symptoms often experienced are key factors in the development of uncertainty. It has also been acknowledged that the lack of treatment may feed into a sense of isolation from others and of anxiety (Horn & Campbell, 2004). This sample identified fears about the cancer spreading and a lack of control as key unmet needs, both needs with the potential to feed into the anxiety that has been highlighted in previous works. In this thesis, the findings were relevant to watch and wait patients that included a diagnosis of CLL as well as participants with NHL, really highlighting the applicability of uncertainty across diagnosis when watch and wait is utilised.

The results highlighted that there were statistically significant differences in unmet need, depression and QoL between watch and wait patients and those actively treated. This is in direct contrast to previous research that has compared psychological outcomes between these groups. Reseach investigating the QoL of CLL patients found no difference between treatment modalities (Holzner et al., 2004); a finding also supported by Levin and colleagues who focussed on anxiety, depression and QoL outcomes (Levin et al., 2007). The sample in the current study also included NHL and myeloma patients in addition to CLL participants, and this potentially explains some of the variation in findings. The present study also recruited patients at the time of diagnosis, again unlike the two existing studies that offer different findings. It is possible that watch and wait patients therefore initially have a better quality of life and psychological wellbeing than their peers who receive treatment, but that overtime, the uncertainty of living with a cancer diagnosis and

prognosis and lack of control (the key unmet needs highlighted for this group), may act to reduce wellbeing lessening the difference between active treatment patients. This study also found that CLL patients have a better QoL than participants with NHL or myeloma, lending support to the hypothesis that having a mixed diagnosis sample may be in part the reason why this study found a significant difference between treatment groups. The scarcity of research into the psychological wellbeing of this patient group means that the body of evidence has not yet reached saturation with regards to how we understand differences between haematological cancer patients that are treated and those that are not.

Study Evaluation

While this study certainly improved the existing knowledge base relating to psychological wellbeing in haematological cancer patients, it must be acknowledged that the work has limitations. The key issue within this study, as highlighted previously, was the small number of participants. In quantitative research, small sample sizes can create concerns about the analysis having sufficient statistical power. Previous literature has highlighted that women are more likely to report unmet needs (Hodgkinson et al., 2007) than men. While this was the trend within this study, t tests to examine gender differences within the sample found no statistically significant differences. While it may be the case that these gender differences were simply not present within the current sample, it must also be acknowledged that the small number of participants (males = 24, females = 10) may have resulted in a lack of power. Power calculations indicate that, with expectations of a medium effect size and power at 0.8, a sample size of 82 would have been required for the t test to have been sufficiently powered to achieve a significant result.

Various attempts were made to improve recruitment, including the researcher being based on site within the out-patient clinic at each site each week. This allowed for the integration of the researcher into the clinical environment, ensuring that clinic lists were screened for potential participants and that clinicians were introducing potential participants to the study. This also typically allowed for a face-to-face meeting between the researcher and the participant, meaning that any queries or concerns about the study can be addressed and the work is humanised by the presence of a recognised point of contact. This limited the number of different hospitals with which the researcher could work however. If recruitment had been undertaken from double or even triple the number of hospital sites,

then the desired number of participants would have been more likely to have been reached but this was not feasible given the time demands and scope of the PhD project. In larger scale studies where support is provided by cancer research networks (e.g. in the form of research nurses), then recruiting from large numbers of sites becomes much more feasible. For the current study, it was felt that maintaining the researcher presence in hospital clinics was the best solution to the challenges of recruitment. For future research projects, these limitations really highlight the importance of research that takes place within a larger, preferably multidisciplinary team so that the workload can be shared within, enabling larger scale recruitment and a higher degree of engagement from within the clinical setting itself.

Clinical Implications

This work has established the presence of a relationship between unmet needs and psychological wellbeing in haematological cancer patients. This both adds to the existing evidence base on how we conceptualise need, but also lends weight to the argument that needs assessment should be integrated into routine practical within the clinical setting. In the UK, holistic needs assessment is becoming more routine within cancer care in line with NICE recommendations that patients should receive individualised care and support not just for the medical care but also for their emotional, spiritual and social wellbeing (NICE, 2004). The knowledge that needs assessment can not only be used as a tool to guide healthcare professionals in their provision of support for their patients, but also has the potential to act as an indicator of a patient's more general psychological health and wellbeing has clear implications for use within the clinical setting.

This study found that unmet needs are significantly correlated with anxiety, depression, QoL and coping. Unmet psychological needs have particular utility in having a relationship with psychological outcomes. In the correlational analysis unmet psychological need correlated with anxiety, depression and coping. Seven needs items in particular were identified that significantly correlated with all of these outcomes, five of which were needs from the psychological need domain and the remaining falling within the sexual domain. The relationship between unmet psychological need and psychological wellbeing is perhaps intuitive: where patients have unmet psychological needs then they also are more likely to have poorer psychological outcomes. But it is also useful in that it provides an indication of specific areas or questions on a needs assessment that are most likely to provide clinicians

with an more general indication of overall psychological health. In order for research and clinical practice to truly integrate, and for these areas of unmet needs to be addressed within the clinical setting, both clinicians and patients must feel comfortable in addressing psychosocial concerns. Work outlined in Chapter 3 of this thesis highlighted that patients can often feel uncomfortable raising concerns that fall outside of a physical remit as this is perceived to be the primary aim of a general hospital (Ozakinci et al., *under review*). However, existing research demonstrates that this is not always an area where clinicians feel comfortable or skilled in discussing either (Fallowfield et al., 2001). Further research is needed that aims to not only improve clinician confidence and feelings of self-efficacy, but this needs to translate through into an improved patient experience. Though there is existing evidence that training programmes can assist here (Moorey, 2013), more work is needed on this aspect of doctor-patient communication. As a health service, it is unreasonable to expect healthcare professionals to have a proficiency in an area where they may have received little training, therefore research is needed to determine the best way of improving both clinician self-efficacy and patient experience at the same time.

The relationship between unmet need and the presence of active treatment was also investigated in this study and highlighted that the relationship was significant across all domains with the exception of health systems and information. This is perhaps logical, in that patients who are receiving active treatment are more likely to be managing adverse physical side effects than watch and wait patients, which may also impact upon psychological and emotional wellbeing (Hong et al., 2014; So et al., 2010). There were no treatment group differences with regards to whether or not patients experienced needs relating to the healthcare system and information provision. This tells us that cancer diagnosis alone is sufficient to induce a need for information and access to healthcare services and clinicians. Physical, psychological, care and sexual needs are more dependent upon the subsequent treatment for diagnosis and all that this entails. While the work here is limited in terms of sample size, and a larger study to further explore these findings would act to strengthen these assertions and produce a more robust evidence base, this work provides a baseline of knowledge that relates to both unmet need and psychological wellbeing in haematological cancer patients. The findings presented here suggest that all haematological cancer patients have a requirement for relevant information, and this has real applications in terms of intervention development and support provision. Information provision was also highlighted in the qualitative work outlined in Chapter 3, along with the assertion that information needs to be tailored to the individual and their specific situation

and their desire for knowledge, thus a consistent narrative is emerging across the collection of studies.

In summary, this research has highlighted the key areas of need for haematological cancer patients and this is in line with the previous findings highlighted within this thesis. The relationship between unmet need and psychological wellbeing has been established in this work and this has significant potential implications for the provision of support services for cancer patients and will be investigated in more detail in the following chapter.

Conclusions

This quantitative questionnaire study has identified key unmet needs for newly diagnosed haematological cancers and highlighted the potential predictive utility of unmet psychological need in enabling clinicians to gain a more general idea of overall patient psychological wellbeing. The routine assessment of unmet needs within the cancer setting has a direct relevance to the provision of relevant, desired support services by enabling healthcare professionals to gain an understanding of not only patient concerns but where their desire for help lies. This study highlights key areas where there is the potential for unmet needs to be present in newly diagnosed haematological cancer patients, beneficial to clinicians conducting appointments in a time-sensitive clinic setting. In addition, this work provides an indication that needs assessment could be used in a broader sense to provide an indication of a patient's overall psychological health. More research is needed to better understand the nature of the relationship between need and psychological wellbeing in order to be more effective in the detection of distress and as a precursor to the development of interventions that are able to target active mechanisms of change, thereby maximising efficiency and impact. This will be expanded upon in the subsequent chapter (Chapter 5) which will detail a quantitative study investigating potential moderators between need and outcome.

The major limitation of the present study was the significant challenge of recruiting participants. Attempts made to improve both recruitment and response rates were outlined earlier within the methodology section of this chapter. It is likely that small numbers of potential participants directly relates to the lack of previous research relating to haematological cancers. This is not a concern that is specific to this patient group however, rarer cancers in general are less likely to be the subject of research in psycho-oncology and the majority of existing research has related to women with a diagnosis of

breast cancer. While there is merit in seeking to recruit patient groups where there is a greater certainty of achieving the desired number of participants, where this becomes at the expense of research in smaller groups, real gaps in the evidence base begin to form. There have been arguments made that, as a field, psycho-oncology needs to be moving forward from descriptive research to create studies that focus on the design and implementation of interventions that reduce distress (Moorey, 2013). Yet for this next stage of research to have real scope and meaning, the evidence base on which it builds must be cohesive and representative of cancer patients as a whole population, rather than on the assumption that all will have psychological needs that fall in line with those of the more common diagnoses. For an intervention to be truly effective and for patient outcomes to improve, then the intervention must be relevant to those patients for whom it aims to produce change. Studies such as the one outlined in this thesis chapter have a real value in that they broaden the knowledge of how rarer cancer diagnoses affect psychological wellbeing and only from a unified understanding of patient need can truly effective interventions be developed. As a result of the issues arising within this chapter, Chapter 6 will seek to broaden the discussion of researching rarer cancer diagnoses in the UK and to argue the case as to why research of this nature is needed.

Chapter 5 - The Long-Term Unmet Needs of Haematological Cancer Survivors and the Role of Psychological Flexibility in their Relationship with Psychological Wellbeing

Overview

Attempting to identify type and prevalence of unmet need in haematological cancer patients has been an on-going research question throughout this thesis. This next chapter will build upon the previous work in an attempt to address the question of whether unmet needs endure after the initial shock of diagnosis and the challenges of treatment have ended into the survivorship phase of cancer. This study will aim to identify the type of unmet needs that are most relevant to survivors and investigate the precise nature of the relationship between needs, wellbeing and the potential factors that may play a role in moderating this relationship. Knowledge of this type is important to inform interventions to potentially improve patient outcomes. Specifically, this study explored the nature of psychological flexibility, that is whether people are able to adapt their thinking patterns in light of a change in their circumstances, and whether this moderates the relationship between unmet need and outcomes in this sample.

Survivorship: An on-going need for support.

Cancer survivorship, described as living with and beyond cancer, is a field of research that is becoming increasingly important: the number of people surviving a diagnosis of cancer is currently estimated to be at around two million (NCSI, 2013) and expected to rise further (Maher & McConnell, 2011). An understanding of the issues experienced by cancer survivors has developed over recent years, and the introduction of initiatives such as the National Cancer Survivorship Initiative (NCSI), resulting from the Cancer Reform Strategy (DoH, 2007) in the UK in 2007, has meant that the wellbeing of patients at this stage of their cancer experiences has been brought into the spotlight. The Improving Outcomes Strategy for Cancer (DoH, 2011) highlighted that more research was needed in order to

determine better ways of ensuring that cancer survivors were able to return to a full and active life after their cancer treatment was completed. A recent report published by the Department of Health (2012) on the quality of life of cancer survivors highlighted that, in comparison to patients with breast, colorectal or prostate cancer, patients with a diagnosis of Non-Hodgkin's lymphoma (NHL) demonstrated comparatively poor psychosocial outcomes. NHL patients displayed worse levels of maintaining their independence, of anxiety, having the biggest problems completing their usual activities, the most difficulties in planning for the future, the most problems with benefits and displayed the highest levels of pain and discomfort. This major report surveyed patients who received their diagnosis a year or more previously, indicating that psychosocial issues continue to affect patients long after their initial diagnosis and often after initial treatment has been completed. While these findings relate to NHL only, and not haematological malignancies as a whole, given the overarching similarities that exist within this group of cancers, it seems likely that this concerning view of wellbeing is generalizable. There is little research that encompasses the spectrum of haematological diagnoses, making further exploration vital to be able to identify their unmet needs.

Previous research on unmet needs in cancer survivors has suggested that 64% have at least one unmet need (Siu et al., 2013), yet there is less indication in the literature regarding the saliency of unmet needs during this time period. Survivorship has in itself been described as an unmet need for cancer patients (Wolff et al., 2005) due to the fact that the levels of support and guidance received by patients typically reduces during the time after treatment ends. Indeed, a study by Lobb and colleagues (2009) included in the systematic review (Chapter 2), indicated that almost two thirds of patients would have liked the opportunity to talk to a HCP about their cancer experiences.

There is little research that looks at the long-term care needs of haematological cancer survivors. Three recent papers have been published based upon a study carried out in Australia that highlight that managing tiredness is a key concern for both Australian and Canadian patients (Hall et al., 2013). This work acknowledges the potential differences that may exist between needs of patients in different countries, and the presence of the National Health Service in the UK (as opposed to a privatised healthcare system) may well serve to minimise some areas of need that are more relevant elsewhere. Further work to emerge from this same research project indicated that 25% of haematological cancer survivors surveyed had a 'high/very high' level of unmet need on multiple items (Hall et al.,

2014). This provides a real suggestion that haematological cancer survivors do experience on-going unmet need that warrants further exploration to both confirm these findings and to form a comparison within a UK sample.

Fear of recurrence is a known psychological concern for cancer survivors (Rogers et al., 2010) and the concern that the cancer could return or spread can be enduring and intrusive for a significant subset of patients. The identification of which patients will develop such fears has been difficult (Llewellyn et al., 2008) with further research needed to highlight any key patient demographics or trigger variables. Survivors also report unmet needs relating to on-going fatigue, altered fertility or body image as a result of treatment and difficulty adjusting to normal life after experiencing a life altering change (Hammond et al., 2008; Harrison et al., 2009). Re-engaging with employment is an additional challenge that many patients must face and uncertainty around finances or being unable to find employment after having had cancer can also significantly impact upon psychological wellbeing in cancer survivors.

There are high levels of undetected anxiety and depression reported in haematological populations (Zittoun et al., 1999) and feelings of powerlessness and loss of control can impact upon a person's wellbeing (Rydahl-Hansen, 2005). A recent report published by the Department of Health (2012) highlighted that, in comparison to patients with breast, colorectal or prostate cancer, patients with a diagnosis of Non-Hodgkin's lymphoma displayed the poorest levels of maintaining independence, of anxiety, having the biggest problems completing their usual activities, the most difficulties in planning for the future, the most problems with benefits and displayed the highest levels of pain and discomfort. This report surveyed 3,300 patients who received their diagnosis a year or more previously, indicating that psychosocial issues continue to affect patients long after their initial diagnosis and often after initial treatment has been completed.

Previous research has indicated that haematology patients experience a lower overall quality of life in comparison to healthy controls (Holzner, 2004). One factor that may feed into the lower QoL observed in some cancer patients is the level of uncertainty faced. Mishel's (1999) Uncertainty in Illness Model (as reviewed in Chapter 4) highlights how important structure providers such as social support, the relationship with the healthcare team or knowledge about their condition, along with stimuli frame, for example the consistency of symptoms or familiarity of events, are in establishing the level of uncertainty that a patient will feel. Much of this work has come out of research conducted with

gynaecological, breast and prostate cancer patients, however, a review of uncertainty in indolent Non-Hodgkin's lymphoma patients found that interventions designed to reduce uncertainty also reduced depressive symptoms and improved QoL (Elphee, 2008).

The on-going presence of unmet psychosocial needs in survivorship is indicative of a wider problem experienced by cancer patients: during their diagnosis and treatment phases, contact with the hospital is regular and patients can be comfortable that they will be able to seek medical support or reassurance from their treating clinicians in a relatively short time frame should the need arise. Once treatment ends however, patients typically go from this sense of security that comes from on-going contact with their clinicians to being seen at much greater intervals for follow-up appointments (Abrahamson, Durham, & Fox, 2010). This can result in feelings of sudden isolation or being abandoned at a time when research indicates that the deeper psychological impact of cancer can come into play (Lobb et al., 2009). A systematic review by Harrison and colleagues (2009) found that although the highest level of need was present at the onset of treatment, a greater number of patients expressed at least some need in the period after treatment ended. The literature relating to the unmet needs of haematological cancer survivors is sparse: there are only two papers that directly examine the unmet needs of this specific group (Hall et al., 2014; Lobb et al., 2009) and one (Hall et al., 2014) details the psychometric evaluation of a needs assessment tool within this group rather than the specific needs of patients. Both of these studies were carried out in Australia; none exist that have recruited a UK based sample. There is, therefore, not only a lack of research relating to the unmet needs of haematological cancer survivors generally, but a dearth of evidence regarding survivors living in the UK.

Unmet psychosocial needs are thought to be directly related to the level of distress that a person might experience upon learning that they have a diagnosis of cancer (Carlson, Waller, & Mitchell, 2012). Indeed, previous researchers have postulated a direct link between unmet need and distress, equating the level of psychosocial need with degrees of emotional or psychological distress (McIllmurray et al., 2001). It is, therefore, possible that the level of unmet psychosocial needs may have an additional clinical application and be used as a more general indicator over overall psychological wellbeing.

The research relating to interventions that aim to reduce unmet needs in cancer patients has yielded variable results (Stanton, 2006). Current practice is typically such that clinicians aim to meet patient need in a more informal manner via the development of a trusting

relationship between patient and clinician, in some cases active listening has been employed as a way of trying to meet needs (Moorey, 2013). More common are interventions that aim to reduce distress or to improve quality of life in cancer patients (Sheard & Maguire, 1999). Both previous work in this thesis and past literature (Armes et al., 2009; Morrison et al., 2012) has highlighted a relationship between unmet needs and psychological wellbeing. It is not clear to what extent unmet needs persist into the survivorship phase for haematological cancer patients in the UK and whether the relationship with wellbeing is maintained. In addition, causality within the relationship between unmet need and wellbeing is not well understood. It may be that the presence of unmet needs is in itself distressing and directly impacts upon psychological health; or, conversely, that the presence of distress may itself be the unmet need being identified. A lack of understanding around the precise nature of this relationship and any additional factors that may also impact upon the nature of the relationship makes designing interventions that will effectively target the processes of change and act to reduce distress more difficult. Interventions that aim to reduce unmet need also often take place within the hospital setting where at the most basic level interventions have focussed on developing the communication skills of clinicians (Merckaert et al., 2005; Fallowfield et al., 2002). This may not adequately account for needs that predominantly affect patients in external settings such as home or work and, as with many areas of research within psycho-oncology, research into this has been carried out with relatively limited cancer samples. More specialised interventions are available and typically provided by trained mental health professionals, yet referral requires the presence of a higher level of distress; this goes somewhat against the stance of developing interventions to reduce unmet need in order to prevent distress from arising in the first place. Understanding the psychological mechanisms affecting the relationship between unmet needs and wellbeing creates the potential for the creation of interventions that accurately target the active mechanisms that exist with a relationship, enabling the intervention to be honed and streamlined (Stanton et al., 2012). If an intervention can target specific factors that have the ability to create change in a person's wellbeing while minimising additional content, then the cost of the intervention can be kept to the minimum required for positive change: highly desirable within a climate of limited resources within the healthcare system.

Moderation

Moderation analysis is a statistical technique that tests for interaction effects using linear regression analysis (Hayes, 2013). It can be used to highlight factors that influence the way

in which a relationship functions; if something acts as a moderator, then, as a variable, it alters the strength or direction of the relationship between the predictor and outcome variables (Hayes, 2013). Moderation effects can manifest in a number of ways: enhancing, buffering or antagonising. If a moderator variable acts to enhance the relationship between predictor and outcome, then when the moderator increases, so does the effect of the predictor variable. If the moderator buffers, then increasing the moderator decreases the effect of the predictor on the outcome variable. In the case of antagonistic moderators, increasing the moderator reverses the effect of the predictor.

Within the broader health literature, techniques such as moderation can be used to advance research into relationships between variables in order to be able to investigate the underlying mechanisms via which relationships function (MacKinnon & Leucken, 2008). Within this literature, moderation has been employed to ask questions such as when are stress levels associated with cardiovascular risk (Mausbach et al., 2008) or to refine the use of interventions by identifying the active mechanisms via which change can occur, for example in indicating that a couples-focused program is more effective for breast cancer patients who display higher level emotion-processing skills at the start of the intervention (Manne et al., 2007).

The influence of additional factors that may affect the relationship has not yet been explored in the context of unmet need and psychological wellbeing. As such, it not yet understood precisely how the relationship between unmet need and distress functions or what the active mechanisms are that affect change in wellbeing. Developing this understanding is pivotal to the development of empirically based interventions that can directly target areas that will be most effective in influencing change (Stanton et al., 2012). Acceptance is a key issue for cancer patients, as one participant from the IPA study (Chapter 3) stated:

"you have to get into a position mentally where you accept… rather than fear" P1

Psychological flexibility is central to self-acceptance (Hayes et al., 2006); a person who is psychologically flexible is able to sit with unwanted experiences rather than trying to avoid or alter them in some way (Fledderus et al., 2013). Someone who was psychologically inflexible may find it difficult to appreciate the context of a situation and to identify behaviours that are aligned to their valued and preferred way of living (Hayes et al., 2006). Being psychologically flexible is, in part, the ability to adapt to new situations and the

demands that are placed upon us. Receiving a diagnosis of cancer, for most people, will mean significant changes in their daily activities, the ability to fulfil previous roles and can ultimately impact upon their view of themselves (Lobb et al., 2009). This can mean that the goals that a person may have previously held may no longer be possible, or that the values that a person holds most important are re-evaluated. It is well recognised that after being diagnosed with cancer, more emphasis is often placed upon relationships and living life as people always wanted to (Sears et al., 2003). Such shifts in perspective are a key component of psychological flexibility (Hayes et al., 2006).

Psychological flexibility is an important construct to explore in this context as it is also thought to be a process of change within Acceptance and Commitment Therapy (ACT; Hayes, Stroshal, & Wilson,2011 ; Ciarrochi, Bilich, & Godsel, 2010): as such, identifying whether this an important construct within cancer adjustment might inform the development of supportive care interventions. ACT is an evolved form of cognitive behavioural therapy (CBT), that sets itself apart from traditional CBT based upon the highly behaviourist view of psychology that this newer form of therapy utilises (Ciarrochi & Bailey, 2008). Rather than challenging distressing thoughts, the central tenet of ACT is that thoughts and distress are accepted as a normal aspect of everyday life, and then 'defused' using a variety of techniques (Hayes et al., 2011). In ACT, psychological acceptance of a situation is thought of as patterns of behaviour rather than as negative cognitions and therefore the main aim of research that uses ACT-based concepts is to understand how to predict and influence acceptance of a situation rather than to change a person's internal cognitions. The efficacy of ACT has been highlighted within multiple settings. Much of the existing literature stems from the application of ACT within a clinical psychology setting (Ruiz, 2010), yet, given the recognised co-morbidity between cancer and distress, there is an argument that interventions that are successful in improving mental health would not also be effective when these problems are co-morbid to physical illness (Hulbert-Williams et al., 2014). Indeed, the evidence base for ACT and physical health concerns is growing with benefits reported for chronic pain (Dahl, Wilson, & Nilsson, 2004), cancer (Hulbert-Williams et al., 2014) amongst others. Within psycho-oncology, psychological flexibility has been utilised as a component of a behavioural change intervention in colorectal cancer survivors (Hawkes et al., 2009) and it has been demonstrated that living a value-centred life was associated with decreased levels of distress in cancer patients (Ciarrochi et al., 2010). Psychological flexibility has also been cited as the possible process of change via which ACT exerts its effects on improving mental wellbeing in adults with mild to moderate depression

and anxiety (Fledderus et al., 2013), indeed it is generally accepted that a measure of psychological flexibility can be utilised as the outcome measure for change resulting from an ACT intervention.

In an outline of the philosophical and conceptual framework behind ACT, Hulbert-Williams, Storey and Wilson (2014) promote the importance of more ACT based research in cancer, suggesting that it might be a more suitable form of psychological intervention due to the emphasis away from problem-solving and towards acceptance of the distressing nature of the experience. ACT may be particularly beneficial for cancer populations given the way it can be successfully employed in non-clinically distressed populations; ACT does not always need to resemble or be sold as a traditional psychological 'therapy', rather techniques that are central to ACT, psychological flexibility notably, can be beneficial in sub-clinical distress or in normalising fears, especially in cancer survivors. Both of these concepts are far more prevalent and relevant within cancer populations than clinical distress. The scope of interventions that target processes of change that are applicable and can be used to good effect in patients with sub-clinical levels of distress is therefore broader with greater generalisability, key in the current climate of limited resources within our healthcare system.

This study explores the potential nature of psychological flexibility and its role as a possible mechanism of change within the relationship between unmet need and psychological wellbeing. It is expected that there is a relationship between unmet need and psychological outcome and, therefore, that a moderation analysis can be employed to determine what effect psychological flexibility has on this relationship, or the way that unmet need and psychological flexibility interact to influence psychological outcome. A model of this hypothesised relationship is depicted below:

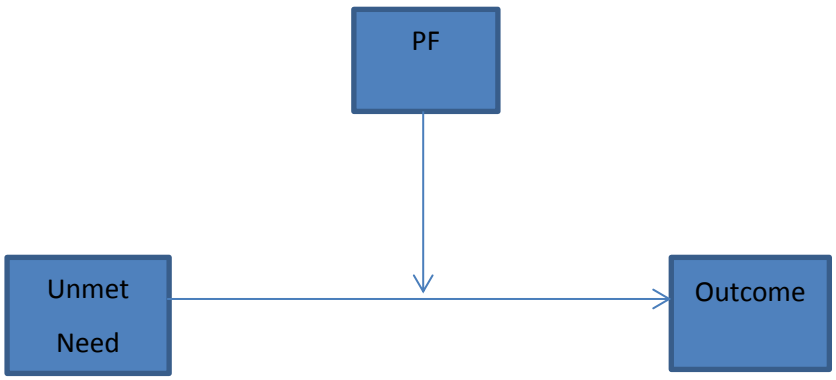

Figure 5.1: Hypothesised moderation model.

Psychological flexibility has been hypothesised as a potential moderator between unmet need and psychological wellbeing for this study in light of the evidence that psychological flexibility is both important to overall psychological health and the proposition that it is the mechanism of change by which ACT produces improvements in wellbeing across a range of patient groups (Fledderus et al., 2013). The decision was made to run a moderation analysis rather than a mediation analysis due to the theoretical underpinnings of the research question: it was hypothesised that psychological flexibility would act as a buffer in the relationship between unmet needs and psychological outcome. That is, people who have high levels of unmet needs were expected to exhibit poorer psychological outcomes. If a person has high levels of unmet needs but also has high psychological flexibility, then this was expected to moderate the psychological impact of the unmet needs and mean that outcomes were better than had the person shown poor psychological flexibility. Conversely, where a person has low levels of unmet needs but is also psychologically inflexible, it was hypothesised that psychological outcomes would be worse than might be expected. This rationale is consistent with moderation (Hayes, 2013) and, therefore, the decision was made to conduct only this method of interaction analysis.

Study Aims

The aims of this study was to answer the question:

What are the long term psychosocial needs of haematological cancer survivors and does the concept of psychological flexibility moderate the relationship between need and psychological wellbeing?

The study objectives were:

1. To identify the unmet psychosocial needs of haematological cancer survivors;
2. To explore psychological wellbeing within clinical and demographic subgroups in line with the study detailed in Chapter 4;
3. To explore the relationship between unmet psychosocial needs and psychological outcomes in haematological cancer survivors with the hypothesis that higher levels of unmet need will result in poorer psychological wellbeing i.e. that as unmet need increases, so too does anxiety and depression while quality of life and psychological flexibility will decrease;
4. To investigate the potential for psychological flexibility to moderate this relationship in a sample of haematological cancer survivors.

Methodology

Study Design

A cross-sectional, questionnaire design was utilised. Participants were assessed for unmet psychosocial needs alongside other psychometric assessments during the survivorship phase of illness.

Sample

All participants were required to fulfil the following inclusion criteria. Due to the nature of recruitment (self-screening inclusion assessment; see below), it must be assumed that participants match these requirements however, it was not possible to verify this.

- Must have, or have had previously, a diagnosis of haematological cancer.
- Must be at least 18 months post-diagnosis.
- Participants must be over the age of 16.

The required sample size was determined using GPower and an expectation of medium effect sizes (Coe, 2002; Cohen, 1988), power at 0.8 and the potential for up to nine variables (anxiety, depression, global QoL, psychological flexibility, each subdomain of the SCNS) to be included within a regression analysis. This calculation indicated that 114 participants would be required to conduct a regression analysis. However, for each individual moderation analysis, there will be one dependent variable, one moderator variable and one outcome variable, therefore reducing the required number of participants for the analysis to be powered.

In total, 91 questionnaires were completed with variable amounts of missing data. Demographic information for the sample is presented in Table 5.1.

Procedure

Ethical approval was given by the University of Chester Departmental Ethics Committee. Participants were recruited via advertisements placed with two of the major UK blood cancer charities: the Lymphoma Association and Leukaemia & Lymphoma Research. Lymphoma Matters is a magazine that is published by the Lymphoma Association that is available online and posted out to subscribers. The magazine has a readership of over 10000, the majority of whom are either people with lymphoma or healthcare professionals. An advert for people who were interested in taking part in a research study was placed in a

quarterly issue of the publication. Leukaemia & Lymphoma Research is a UK based charity who posted an advert directing survivors to the study on their website. All advertisements stated that participants must have received a diagnosis of a haematological cancer a minimum of 18 months previously (Appendix 20).

Table 5.1: Participant demographic information.

Demographic		**Percentage**
Gender	Male	46.80%
	Female	53.20%
Mean Age	61 (12.4)	
Age Range	19 - 97	
Ethnicity	White	
	Black Caribbean	1.30%
	Chinese	1.30%
Employment	Employed	27.50%
	Retired	45.10%
	Fulltime Education	1.10%
	Unable to Work	13.40%
Diagnosis	AML	1.10%
	CLL	19.80%
	CML	2.20%
	Hodgkin	8.80%
	Lymphoma	
	NHL	58.20%
Treatment	Active Treatment	78%
	Watch and Wait	22%

Participants were asked to complete a questionnaire on one occasion only. The questionnaire was either completed online at a web address provided in the advertisement, or participants were able to contact the research team directly in which case the questionnaire (Appendix 21) and debrief sheet (Appendix 22) were posted out to the participant. Information about taking part in the study was made available to all participants whether completing the questionnaire online or via post (Appendix 23). If completing online, participants were required to read the information sheet before they

were able to progress through to the questionnaire itself. Where participants requested that the questionnaire was posted out to them, they also received a printed study information sheet and a pre-paid reply envelope.

After the questionnaire was completed, participants were provided with a debrief sheet containing contact details for appropriate support services. This was either posted out along with the questionnaire to ensure that participants had access to the information contained within as and when it might be needed, or it was the final page of the questionnaire for participants who completed the questionnaire online.

Informed Consent

Prior to completing the questionnaire, participants were requested to read the full information sheet and to contact the research team to ask any questions that they may have before deciding whether or not they wished to take part in the study. The information sheet was available online at the web address provided and was posted out to participants along with the questionnaire.

All questionnaires were completed anonymously and participants were not asked to share identifiable information. Therefore, participants were not asked to sign their consent but it was made clear in the information sheet that by completing the questionnaire, participants were giving their consent for their data to be used in the study.

Confidentiality

No member of the research team had access to any patient information until such a time where the patient had implicitly given their informed consent for their details to be shared by reading the information sheet and completing the questionnaire. All returned questionnaires were stored in a locked cabinet in a secure storage room at the University of Chester. In accordance with the Caldicott Principles, all information was held on a strictly need to know basis. All electronic data was stored on a password protected area on a server at the University of Chester and accessed by BS only with NHW to be allowed access in case of emergency. All data analysis was conducted on university computers. Long-term storage of all documents was in University of Chester secure archives.

Measures

The questionnaire (Appendix 21) included the following measures and was formatted using Formic (survey software that allows for both online and paper completion) to ensure ease of presentation, distribution and scoring:

- Unmet psychosocial needs: SCNS-SF34 (Bonevski et al, 2000). The SCNS SF34 is a 34 item measure designed to assess the unmet needs of adult cancer patients. Need is measured on a likert scale from 1 (no need) to 5 (high need). Domains are as follows: physical and daily living (PDL); psychological (psych); health systems and information (HSI); patient care and support (PCS); and sexual. This measure was chosen over other needs assessment tools due to its wide usage within cancer research as evidenced by the systematic review in Chapter 2 and the fact that is was designed to assess generic needs within cancer patients.

- Anxiety and depression: HADS - 14item (Zigmond & Snaith, 1983). The HADS is a 14 item measure designed to assess levels of anxiety and depression. Answers are ranked from 0-3 for each item. The measure has two sub-domains: anxiety and depression, each with seven items. This measure was chosen due to its wide usage both within cancer research but within the wider health psychology field as evidenced within the literature reviews included within this thesis.

- Quality of life: EORTC QLQ-C30 - 30 item (Aaronson et al., 1993). This is a 30 item QoL tool where items are ranked from 1 (not at all) to 4 (very much). There are nine sub-scales: five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, and nausea and vomiting); and a global health and quality-of-life scale. This measure was chosen due to its common usage within the studies included within the systematic review in Chapter 2 and the fact that it was designed to assess QoL within cancer specifically. While the FACT QoL measure does have both leukaemia and lymphoma specific scales, having different scales in use within the same study was felt to reduce opportunities to draw direct comparisons from across the whole sample. In addition, the EORTC QLQ-C30 was more widely used in the previous literature as highlighted previously, enabling comparisons between this sample and others.

- Acceptance and Action Questionnaire: AAQ-II (Bond et al., 2011). A 10 item measure where items are ranked from 1 (never true) to 7 (always true). This measure was chosen as it is a well validated, general measure of psychological flexibility.

- Demographic questionnaire.

All measures were selected for their appropriateness for the patient group and for their psychometric properties.

For each measure with the exceptions of the cognitive functioning and symptoms-nausea subscales of the EORTC, Cronbach's alpha was above the 0.7 range which is widely accepted as indicating that the measure works for the dataset (Bland & Altman, 1997). Cronbach's alpha for the global score for quality of life however was 0.95, as this was the total that was used within the calculations for both the correlation and moderation analysis, it was felt that all measures represented a good fit with the sample.

Table 5.2: Table to illustrate the Cronbach's alpha for each measure sub-scale used within the study.

Measure	**Cronbach's Alpha**
HADS	Depression 0.84, Anxiety 0.87
EORTC QLQ-C30	Physical Functioning 0.88, Role Functioning 0.91, Cognitive Functioning 0.44, Emotional Functioning 0.89, Social Functioning 0.86, Symptoms - NAUS 0.59, Symptoms - FAT 0.94, Symptoms-PAIN 0.95, Global health score 0.95
AAQ-II	0.88
SCNS SF34	Psychological 0.96, Health systems and information 0.93, Patient care and support 0.88, Physical and daily living 0.93, Sexual 0.88

Data Analysis

Initially, an exploratory analysis was conducted where parametricity of data was determined and the reliability of the measures was explored. Descriptive statistics were then used to explore the data and to form comparisons between clinical and demographic subgroups.

Correlations were used to determine which predictor variables correlate with outcomes. Utilising a correlational design enabled the researcher to examine the direction of any such relationships, the strength of relationships and the statistical significance of relationships. This enabled the investigation of whether unmet psychosocial needs correlate with either

psychological flexibility or outcomes (anxiety, depression, psychological adjustment to cancer and quality of life) such to address hypothesis 3.

In order to determine whether psychological flexibility acts as a moderator between unmet psychosocial need and the outcome variables (hypothesis outlined in Objective 4), a moderation analysis was employed. The macro PROCESS developed by Andrew Hayes was used to perform this part of the analysis (Hayes, 2013). This tool is downloaded into the SPSS software to allow researchers to conduct both moderation and mediation analyses. PROCESS uses an ordinary least squares or logistic regression-based path analytical framework for estimating two and three way interactions in moderation models along with simple slopes and regions of significance for probing interactions. As a tool, PROCESS can be used more broadly for mediation-based analysis, yet these were the uses utilised within this study.

Results

Objective 1: The Unmet Needs of Haematological Cancer Survivors

Examination of both graphical displays (e.g. scatter plots, histograms, Q-Q plots) of the dataset and running Kolmogorov-Smirnov tests for the key variables that were to be included within the correlational and moderation analysis (anxiety, depression, global quality of life score, psychological flexibility and unmet need) determined that the data was normally distributed, that there was a linear relationship and, therefore, parametric testing was appropriate. There was somewhat of a floor effect present on the unmet need sub-scales due to a high number of participants selecting the 'no need' response; however, given that the remaining key variables were normally distributed and the repeated questioning within the related literature with regards to the need for parametric conditions to be met (Bryman & Cramer, 2011), the decision was made to use parametric testing.

In total, participants answered five different measures within the questionnaire. The mean and standard deviation for each sub-scale is presented in Table 3.

Table 5.3 indicates that, across the sample as a whole, the mean scores for both anxiety and depression are below clinically significant thresholds (8 being borderline clinically significant and 10 being clinically significant) although the mean anxiety score is only 0.74 below this threshold. This may be somewhat misleading however, as these same data indicate that 51.4% of the sample are above the threshold for borderline clinically significant anxiety and 27% of the sample are within the clinically significant range. For depression, results show that 27% of the sample is above the borderline level of clinical significance and 12.2% are within the clinically significant range. This makes the levels of anxiety and depression within this sample above the point prevalence rates for either disorder within the general population (Baxter et al., 2013).

Table 5.3: Mean and standard deviation for each sub-scale.

Measure (Sub-Scale)	Mean (SD)
SCNS Physical and Daily Living needs	2.19 (1.20)
SCNS Psychological needs	2.39 (1.11)
SCNS Health Systems and Information needs	1.77 (0.791)
SCNS Patient Care and Support needs	1.83 (0.875)
SCNS Sexual needs	1.91 (1.08)
AAQ-II	50.9 (11.5)
HADS Anxiety	7.26 (4.26)
HADS Depression	5.19 (3.72)
EORTC Physical Functioning	1.70 (0.766)
EORTC Role Functioning	1.89 (0.934)
EORTC Cognitive Functioning	1.56 (0.732)
EORTC Emotional Functioning	1.83 (0.738)
EORTC Sexual Functioning	1.91 (0.892)
EORTC SYMPTOM-FATIGUE	2.15 (0.873)
EORTC SYMPTOM-NAUSEA/VOMITING	1.18 (0.361)
EORTC SYMPTOM-PAIN	1.56 (0.774)
EORTC GLOBAL SCORE	5.01 (1.48)

Regarding unmet needs, Table 5.3 indicates that the domain with the highest area of unmet need is psychological need; the mean score indicates that the average level of need is within the bounds of being present but satisfied. Under ten per cent (9.9%) of the sample had unmet psychological needs that were within the moderate to high need range with almost a third of the sample reporting a need that remained unmet within this domain; similar figures were also reported for the physical and daily living domain. The number of participants reporting an unmet need related to the health systems and information domain was also similar with around one third reporting an on-going unmet need in this area yet fewer reporting their need to be on average moderate to high within this domain. The levels of unmet need present vary considerably from low need to high need within the sample.

Lack of energy/tiredness and not being able to do the things you used to do were the most common high unmet needs (14.3%) within the sample. 12.1% of the sample report

uncertainty about the future as a high unmet need, with concerns about the worries of those close to you having the same percentage reporting high unmet need. High unmet needs relating to anxiety and fears about the cancer spreading were the other two most commonly reported unmet needs at the high level, each present in 9.9% of the sample. Of these six most common unmet needs, four are needs within the psychological domain; this is unsurprising given that psychological need had the highest average score of all five unmet need domains and concurs with information reported in the study of newly diagnosed patients (Chapter 4). Figure 1 presents the mean scores for each individual needs item. Lack of energy/tiredness, fears about the cancer spreading and uncertainty about the future are the three most commonly identified unmet needs on average across the sample.

The anxiety score (on the HADS) and unmet needs responses indicate a discrepancy between the number of participants who scored as being anxious on the HADS and those who report having an unmet need for support relating to anxiety. More participants are anxious than indicate a high desire for help with their anxiety.

Objective 2: Psychological Wellbeing within Clinical Subgroups

Gender Comparisons

46.8% of this sample were male and 53.2% were female. Across all five unmet need domains, women reported higher levels of unmet need than males. On average, men scored higher on the AAQ-II (M = 54.7 (2.28), F = 47.6 (1.96)) meaning that the males in our sample tended to be more psychologically flexible than the women.

Women's mean anxiety scores were within the borderline clinically significant range (8.81 (0.63)) while the male average anxiety score was somewhat below clinical levels (5.38 (0.87)), indicating that women were more anxious as a group than men. Depression scores showed a similar pattern with the female average being above the male average (F=6.26 (0.68), M=3.71 (0.63)) but neither sample average was above the clinical cut off.

The male global quality of life average was above the female average (F=4.77 (0.28), M=5.33 (0.29)) which ties in with the reported scores for both anxiety and depression, the males within our sample reported less distress as a group overall than the females. t tests were used to examine potential differences between genders. No significant differences were found for depression, anxiety or QoL.

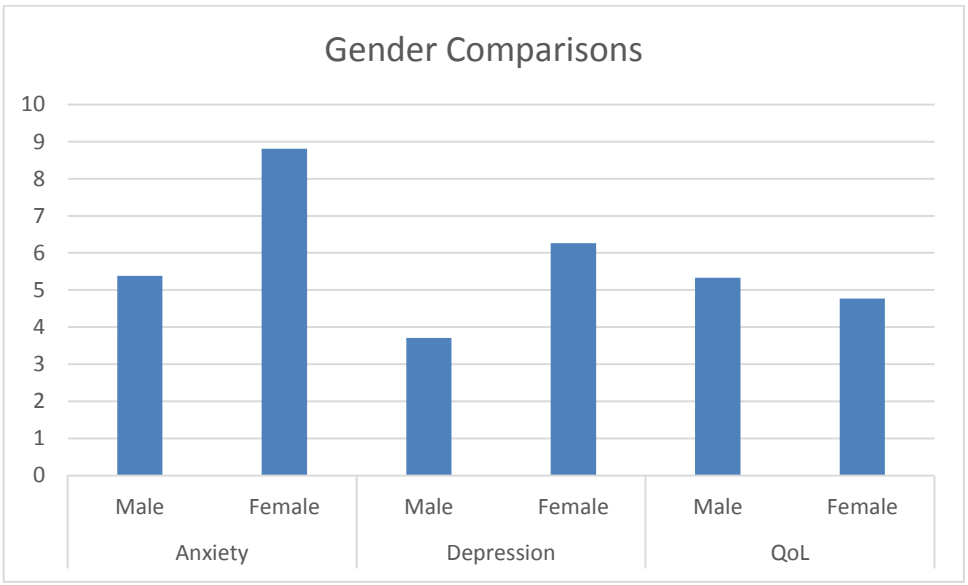

Figure 5.2: Mean gender scores for key outcomes.

Treatment

78% of the sample had received active treatment (AT) for their cancer while 22% had only ever been monitored via watch and wait (WW). The maximum length of time that a

participant had been diagnosed and their cancer managed via watch and wait was nine years although 18 months to five years were more commonly reported.

Those monitored via watch and wait had slightly higher unmet needs in the psychological domain (AT=2.38 (0.16), WW=2.41 (0.36)) and higher unmet needs relating to patient care and support (AT=1.79 (0.12), WW=1.96 (0.32)). In other domains, those who had received active treatment reported higher levels of unmet needs.

The group who were monitored via watch and wait were, on average, more psychologically flexible than those on active treatment (AT=49.6 (1.71), WW=55.0 (3.23)).

For both anxiety and depression, those who had been actively treated scored higher than the watch and wait group (Anxiety AT=7.6 (0.62), WW=6.00 (1.3); Depression AT=5.42 (0.56), WW=4.33 (1.05)) although neither groups mean score falls within the clinically significant range.

Overall quality of life was very similar between the two groups (AT=5.00 (0.21), WW=5.04 (0.49)). t tests indicated that differences between the two treatment sub-groups were not statistically significant.

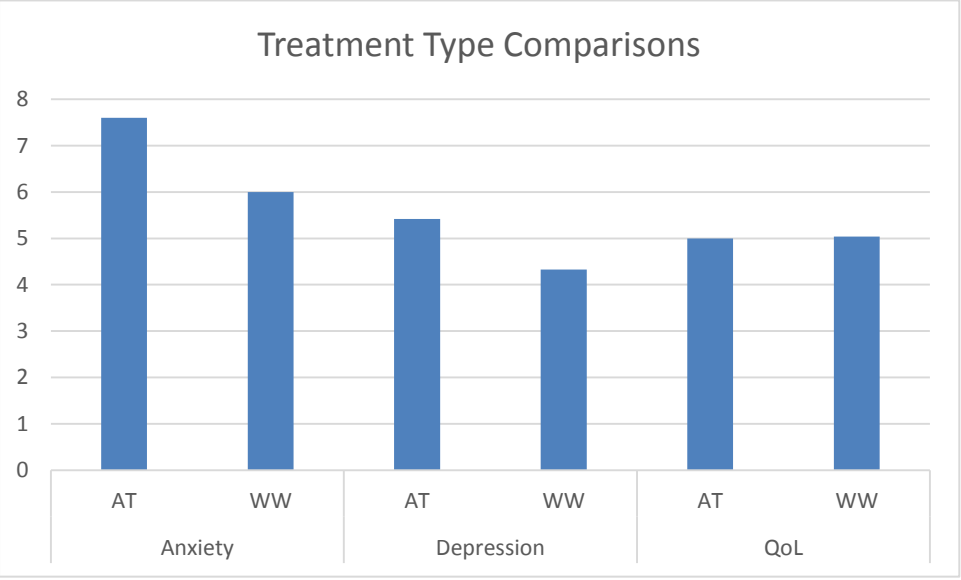

Figure 5.3: Mean scores for treatment groups Active Treatment and Watch and Wait for key outcomes.

Diagnosis

The most common diagnosis within the sample is Non-Hodgkin lymphoma (58.2% of the total sample), this is representative of the haematological cancer population where NHL is the most commonly diagnosed type. Also included the sample were participants with a

diagnosis of AML (1.1%), CLL (19.8%), CML (2.2%) and Hodgkin lymphoma (8.8%), the divisions within the sample were representative of the haematological cancer population.

Participants with CLL have the highest level of unmet needs across all domains assessed with participants with CML typically having the lowest level of need albeit the sample size of participants with CML was small to be make accurate generalisations.

Psychological flexibility was similar in participants with CLL, CML and Hodgkin lymphoma, all scoring between 54 and 55. Flexibility was somewhat lower in participants with NHL with an average score of 49.2. Anxiety levels were also higher in NHL participants at 7.92 with all other groups' average scores around 6. A similar pattern occurred for depression with the NHL score at 5.47 with all other diagnostic groups scoring between 4 and 4.5. The lowest quality of life score however was observed in the CLL group at 4.85. NHL followed at 4.97 with CML the highest scoring at 6.5.

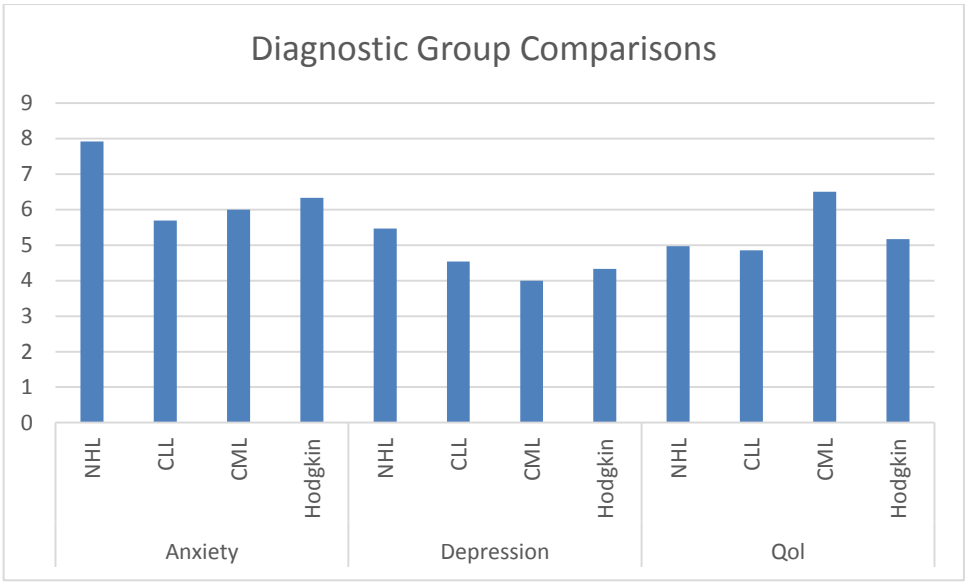

Figure 5.4: Mean scores for key outcomes according to diagnosis.

Objective 3: The Relationship between Unmet Need and Psychological Wellbeing

For this study objective, Pearson's r correlations between unmet psychological need domains and outcomes anxiety, depression and quality of life were tested in addition to psychological flexibility scores.

Table 5.4: Correlations between SCNS sub-scales and outcomes.

		AAQII Total	HADS Anxiety	HADS Depression	EORTC Global
SCNS Physical and Daily Living	r	-.43	.44	.64	-.82
	p	.000	.000	.000	.000
SCNS Psychological	r	-.71	.70	.61	-.57
	p	.000	.000	.000	.000
SCNS Health Systems and Information	r	-.42	.30	.40	-.48
	p	.000	.016	.001	.000
SCNS Patient Care and Support	r	-.55	.42	.52	-.51
	p	.000	.000	.000	.000
SCNS Sexual	r	-.40	.55	.36	-.40
	p	.000	.000	.002	.001
SCNS Total	r	-.65	.58	.65	-.71
	p	.000	.000	.000	.000

The correlations cited within Table 5.4 indicate that there is a relationship present between unmet needs and psychosocial outcomes. All correlations were statistically significant at the 0.01 level (two-tailed test) with the exception of HADS Anxiety and SCNS HSI which was still significant but at the 0.05 level (two-tailed test).

The effect sizes observed were generally within the medium-large range. For the correlations between unmet need total score and each of the measures of wellbeing, three of the effect sizes would be categorised as medium (anxiety , depression and psychological flexibility) and one as large (QoL).

The positive correlation between unmet need and anxiety and depression indicate that where once increases, so does the other, thereby indicating that higher levels of unmet needs correspond with higher levels of anxiety and depression within the sample. The negative correlation between unmet need and both QoL and psychological flexibility means that the opposite is true in this instance, where unmet need increases, the other decreases (and vice versa).

In addition to correlation between total need score, sub-domain scores and outcome variables, correlations between each individual need item on the SCNS SF34 and key outcomes variables anxiety, depression and QoL were performed (Table 5.5).

Table 5.5: Correlation between individual needs items and outcome variables.

		AAQII Total	HADS Anxiety	HADS Depression	EORTC Global
Pain	r	-.33	.37	.55	-.68
	p	.004	.001	.000	.000
Lack of energytiredness	r	-.51	.53	.64	-.77
	p	.000	.000	.000	.000
Feeling unwell a lot of the time	r	-.41	.50	.60	-.71
	p	.000	.000	.000	.000
Work around the home	r	-.34	.34	.51	-.68
	p	.003	.004	.000	.000
Not being able to do things you used to do	r	-.38	.38	.60	-.76
	p	.001	.001	.000	.000
Anxiety	r	-.63	.63	.54	-.58
	p	.000	.000	.000	.000
Feeling down or depressed	r	-.66	.65	.63	-.59
	p	.000	.000	.000	.000
Feelings of sadness	r	-.64	.67	.66	-.53
	p	.000	.000	.000	.000
Fears about the cancer spreading	r	-.58	.57	.45	-.49
	p	.000	.000	.000	.000
Worry that the results of treatment are beyond your control	r	-.56	.51	.35	-.31
	p	.000	.000	.002	.008
Uncertainty about the future	r	-.74	.69	.57	-.47
	p	.000	.000	.000	.000
Learning to feel in control of your situation	r	-.50	.52	.36	-.39
	p	.000	.000	.002	.001
Keeping a positive outlook	r	-.66	.61	.53	-.54
	p	.000	.000	.000	.000
Feelings about death and dying	r	-.60	.57	.49	-.49
	p	.000	.000	.000	.000
Changes in sexual feelings	r	-.35	.52	.36	-.45
	p	.002	.000	.002	.000
Changes in your sexual relationships	r	-.34	.53	.35	-.44
	p	.002	.000	.002	.000
Concerns about the worries of those close to you	r	-.42	.46	.31	-.44
	p	.000	.000	.008	.000
More choice about which cancer specialists you see	r	-.44	.29	.43	-.36
	p	.000	.011	.000	.002
More choice about which hospital you attend	r	-.45	.26	.44	-.36
	p	.000	.025	.000	.002

Reassurance by medical staff that the way you feel is normal	r	-.48	.45	.50	-.51
	p	.000	.000	.000	.000
Hospital staff attending promptly to your physical needs	r	-.43	.42	.47	-.45
	p	.000	.000	.000	.000
Hospital staff acknowledging and showing sensitivity to your feelings and emotional needs	r	-.45	.29	.34	-.40
	p	.000	.012	.003	.000
Being given written information about the important aspects of care	r	-.26	.29	.39	-.47
	p	.028	.014	.001	.000
Being given information written diagrams drawings about aspects of managing you illness and side effects at home	r	-.28	.34	.40	-.41
	p	.015	.003	.001	.000
Being given explanations of those test for which you would like explanations	r	-.24	.21	.27	-.25
	p	.036	.068	.020	.033
Being adequately informed about the benefits and side effects of treatments before you choose to have them	r	-.36	.34	.38	-.31
	p	.002	.003	.001	.008
Being informed about your test results as soon as feasible	r	-.29	.09	.25	-.38
	p	.013	.432	.033	.001
Being informed about cancer which is under control or diminishing that is remission	r	-.36	.28	.34	-.41
	p	.001	.016	.003	.000
Being informed about things you can do to help yourself to get well	r	-.45	.52	.43	-.45
	p	.000	.000	.000	.000
Having access to professional counselling eg psychologist social worker counsellor nurse specialist if you family or friends need it	r	-.48	.51	.38	-.35
	p	.000	.000	.001	.003
Being informed about sexual relationships	r	-.41	.45	.27	-.16
	p	.000	.000	.020	.175
Being treated like a person not just another case	r	-.36	.27	.30	-.36
	p	.002	.022	.011	.002
Being treated in a hospital or clinic that is as physically pleasant as possible	r	-.27	.11	.17	-.13
	p	.022	.344	.157	.293
Having one member of staff with whom you can talk to about all aspects of your condition treatment and follow up	r	-.48	.35	.33	-.40
	p	.000	.002	.004	.001

Table 5.5 shows the correlation between individual needs items on the SCNS SF34 and the outcome variables. For 30 out of 34 items, all correlations were statistically significant at $p \leq 0.05$ for all variables indicating that a majority of items on the SCNS SF34 have a utility in providing an indication of overall psychological health.

These results indicate that there are statistically significant relationships between the level of unmet need and psychological wellbeing. The positive correlations between unmet need and both anxiety and depression indicates that high levels of unmet need are likely to

correspond with high levels of anxiety and depression. The negative correlations between unmet need and both psychological flexibility and quality of life indicate that higher levels of unmet need are likely to be accompanied by lower quality of life and psychological flexibility. In essence, high unmet needs correlate with poorer psychological outcomes. Most notable are the correlations between global QoL and unmet physical and daily living needs and between psychological flexibility and unmet psychological needs. Both are strong negative correlations that indicate that a high unmet need relates to lower QoL or psychological flexibility in these instances. It is important to acknowledge however, that when a large number of tests are performed, the likelihood of Type I error increases. However, as with Chapter 4, the decision was made not to include Bonferroni corrections within the analysis. Again, due to the overly conservative nature of Bonferroni corrections, which can create liability for a Type II error (Cohen, 1994), and in light of the arguments made for other testing procedures (Bender & Lange, 1999) in addition to the consistency of the results with both the hypothesis stated under the study aims and the wider literature, Bonferonni corrections were not used.

Objective 4: Moderation Analysis

Subsequent to the correlation analysis, the final step in the analysis process was to conduct a moderation analysis addressing whether psychological flexibility might act as a moderator between unmet psychosocial needs and psychological outcomes. In total, 15 moderation analyses were performed: each of the five needs sub-scales against anxiety, depression and quality of life, all with psychological flexibility as the moderator. Four significant moderation effects were found:

The relationship between unmet psychological needs and global quality of life was moderated by psychological flexibility (b = -0.378, 95% CI [-0.0607, -0. 0149], t = -3.297, p = .0016). The model of unmet psychological need predicting quality of life while moderated by psychological flexibility was significant and predicted a total of 41% of variance in quality of life scores (R^2 = .41, *F* (3, 64) = 24.22, *p*<.001). The simple slope analysis demonstrated that the relationship between unmet psychological needs and global quality of life emerges in people with average or above average levels of psychological flexibility. This means that the relationship between unmet need and QoL goes from being non-significant at low

levels of flexibility, to a negative relationship between need and QoL that increases in significance as the level of psychological flexibility increases.

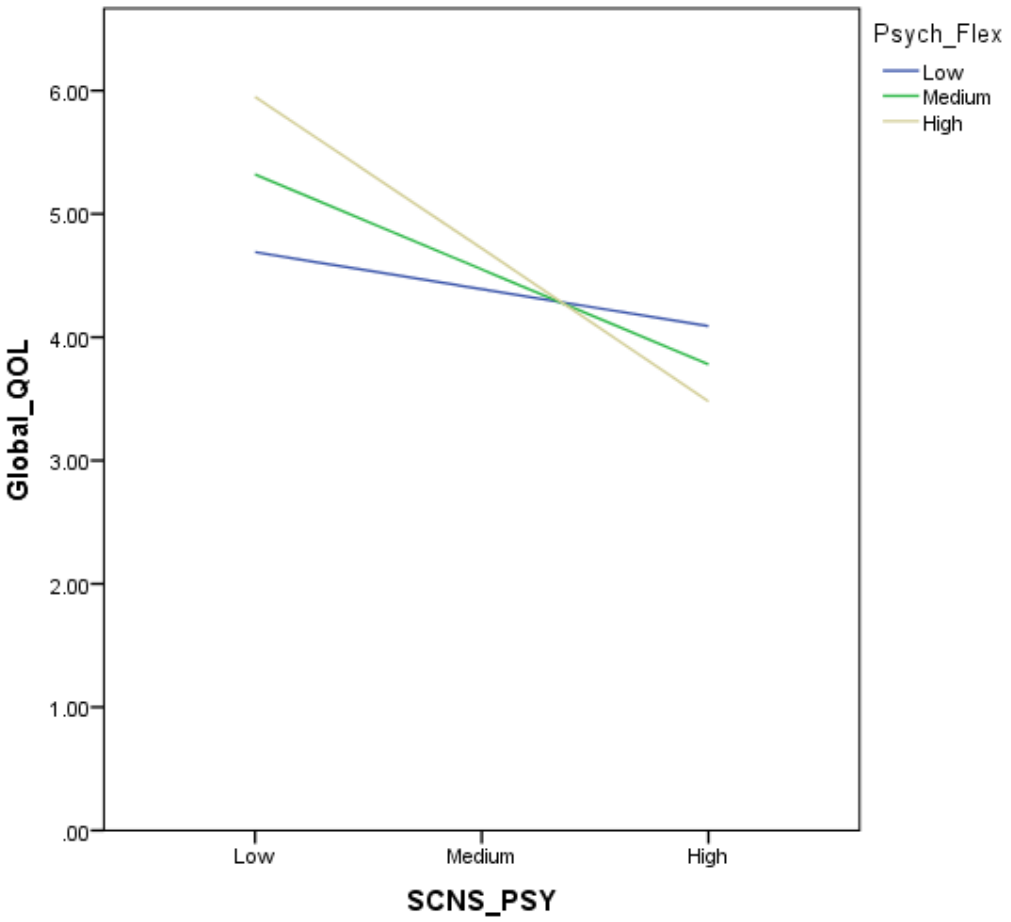

Figure 5.5: Graph to illustrate the relationship between QoL, psychological flexibility and unmet psychological needs.

The relationship between unmet sexual needs and global quality of life was also moderated by psychological flexibility (b = -0.0276, 95% CI [-0.051, -0.0043], t = -2.36, p = .0212). The model of unmet sexual need predicting quality of life while moderated by psychological flexibility was significant and predicted a total of 35% of variance in quality of life scores (R^2 = .35, *F* (3, 66) = 15.77, *p*<.001). The simple slope analysis demonstrated that the relationship between unmet sexual needs and global quality of life emerges in people with average or above average levels of psychological flexibility. This means that the relationship between unmet need and QoL goes from being non-significant at low levels of flexibility, to a negative relationship between need and QoL that increases in significance as the level of psychological flexibility increases.

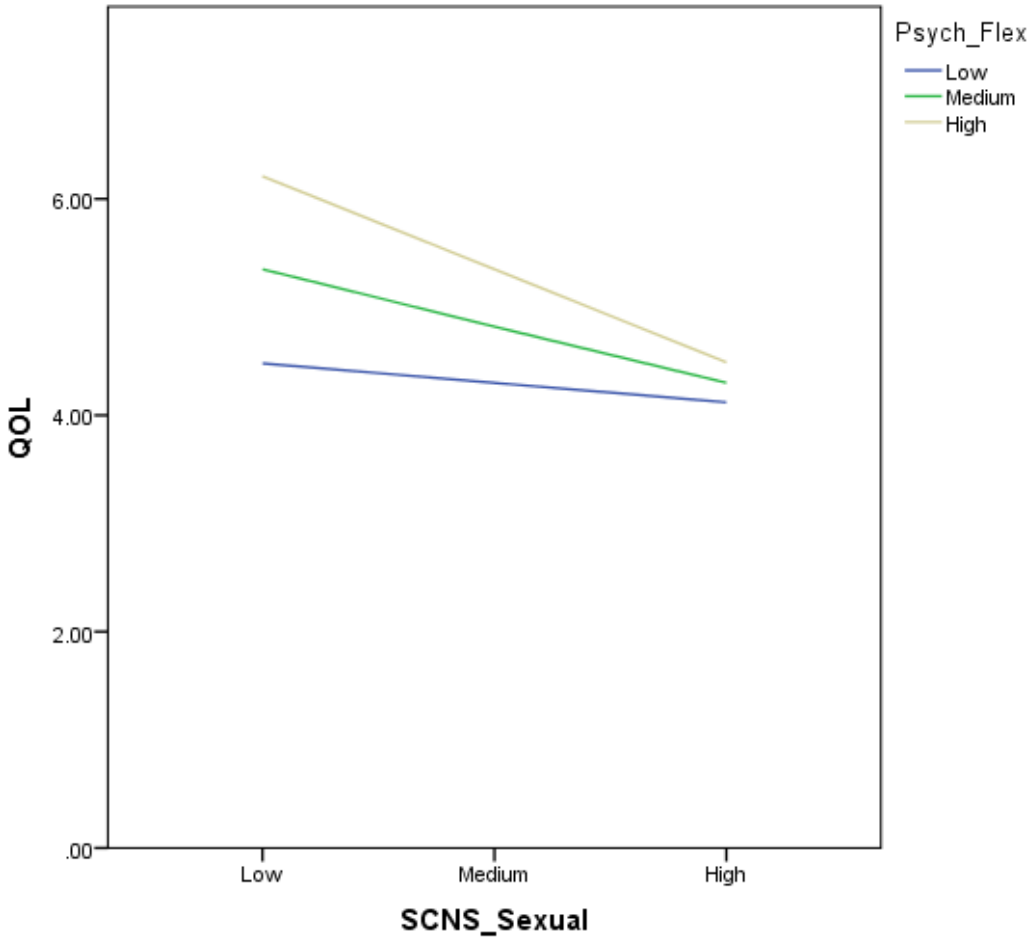

Figure 5.6: Graph to illustrate the relationship between QoL, psychological flexibility and unmet sexual needs.

The relationship between unmet patient care and support needs and anxiety was moderated by psychological flexibility (b = 0.136, 95% CI [0.0390, 0.234], t = 2.79, p = .0067). The model of unmet patient care and support need predicting anxiety while moderated by psychological flexibility was significant and predicted a total of 64% of variance in anxiety scores (R^2 = .64, *F* (3, 70) = 52.1, *p*<.001). The results of the simple slope analysis indicate that the relationship between unmet patient care and support needs only emerges in people with average or above average levels of psychological flexibility. This means that is the relationship between unmet need and anxiety goes from being non-significant at low levels of flexibility, to a positive relationship being present between need and anxiety that increases in significance as the level of psychological flexibility increases.

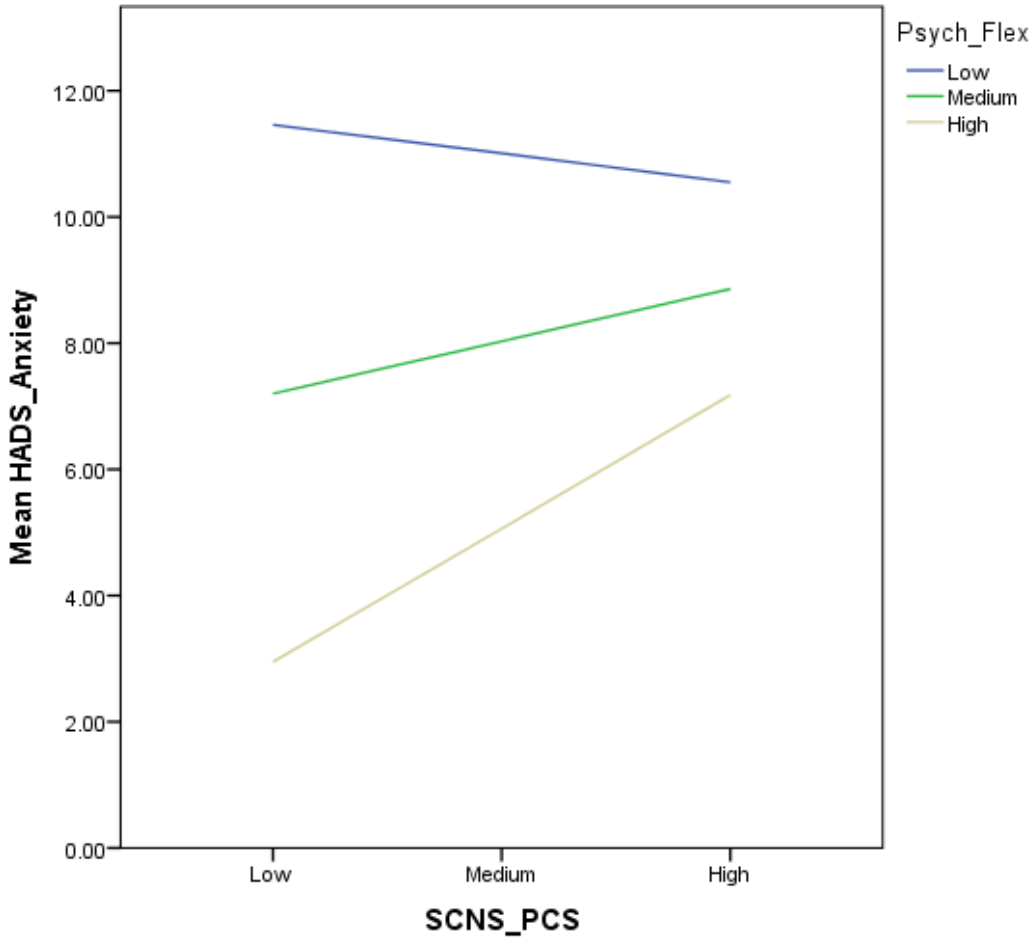

Figure 5.7: Graph to illustrate the relationship between anxiety, psychological flexibility and unmet patient care and support needs.

The relationship between unmet patient care and support needs and global quality of life was the final relationship found to be moderated by psychological flexibility (b = -0.0542, 95% CI [-0.0739, -0.0346], t = -5.50, p = <.0001). The model of unmet patient care and support need predicting quality of life while moderated by psychological flexibility was significant and predicted a total of 44% of variance in quality of life scores (R^2 = .44, *F* (3, 68) = 29.89, *p*<.001). The simple slope analysis demonstrated that the relationship between unmet patient care and support needs and global quality of life emerges in people with average or above average levels of psychological flexibility. This means that the relationship between unmet need and QoL goes from being non-significant at low levels of flexibility, to a negative relationship between need and QoL that increases in significance as the level of psychological flexibility increases.

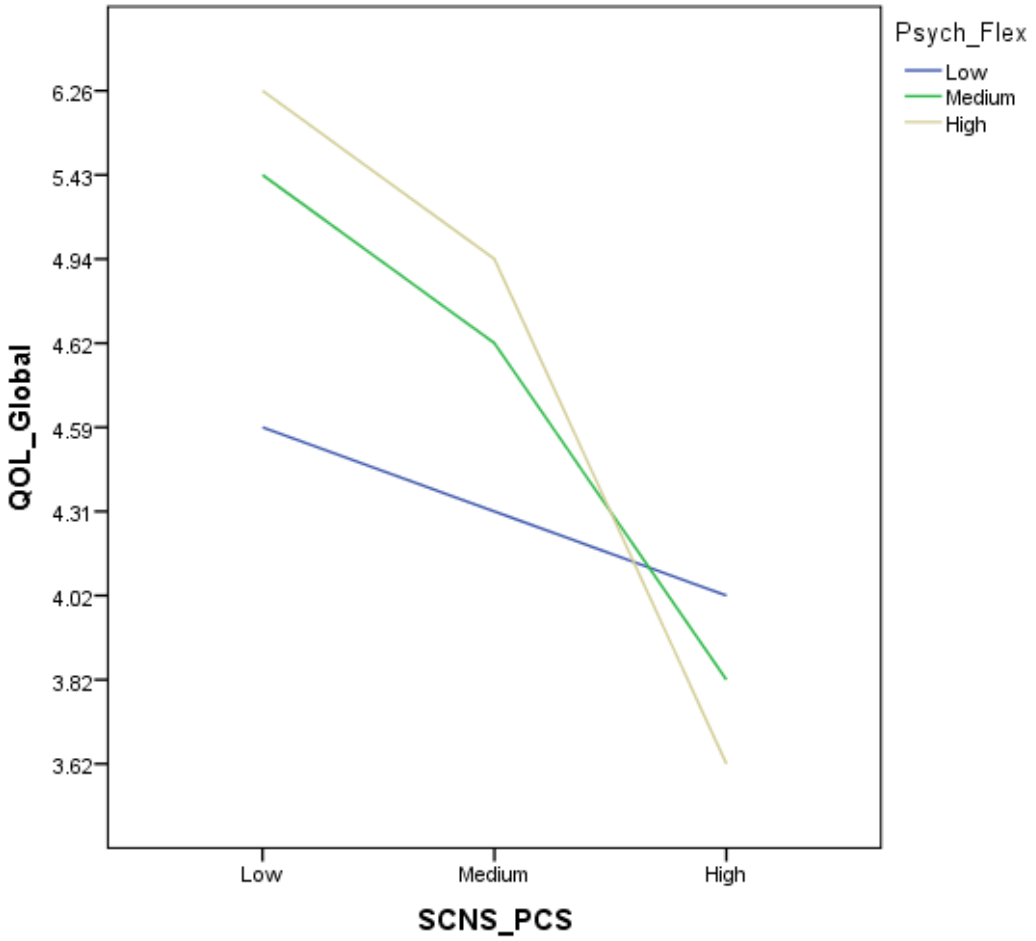

Figure 5.8: Graph to illustrate the relationship between QoL, psychological flexibility and unmet patient care and support needs.

The results of the moderation analysis indicate that psychological flexibility does moderate between unmet need and psychological outcome within specific areas. Further examination also highlights that, where the moderation analysis was found to be significant, the effect of the moderation was partial and that the relationship between psychological flexibility, unmet need and outcome only emerge where average or above average levels of psychological flexibility are present[1].

As with the correlation analysis, it must be acknowledged that performing a high number of statistical tests increases the likelihood of a Type I error.

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[1]Due to the somewhat surprising results of the moderation analysis, further analysis of the data was undertaken. A factorial ANOVA confirms the presence of an interaction in the data and that the findings presented are reflective of the data.

Discussion

The findings of this study expand the findings outlined in Chapter 4 in confirming the presence of a relationship between unmet psychosocial needs and psychological outcomes, this time in haematological cancer survivors. It has also been demonstrated that, for the outcomes anxiety and QoL, psychological flexibility plays a role in moderating this relationship. Psychological flexibility was found to moderate the relationship between unmet needs and psychological outcomes in four of the interactions tested, yet the results were not in line with initial expectations. It was hypothesised that flexibility would buffer the impact of unmet needs on psychological wellbeing, yet the results of the moderation analysis found that the relationship between unmet need and psychological outcome was only present where levels of psychological flexibility were at average or above average levels for the sample. While the findings of both the correlation analysis and the moderation analysis do suggest that psychological flexibility plays a role in the psychological wellbeing of haematological cancer survivors, the precise nature of this relationship requires further consideration.

The Unmet Needs and Psychological Wellbeing of Haematological Cancer Survivors

This study has highlighted the common unmet needs of haematological cancer survivors, an area of research that has been lacking within the existing evidence base. Four of the six most commonly identified unmet needs were psychological needs, lending weight to existing research that has indicated that psychological concerns can persist well after treatment ends (Lobb et al., 2009). This also bears similarities to the findings of the research outlined in Chapter 3. Again, psychological needs emerged as being important to the NHL survivors interviewed and as being unmet within the sample, meaning that the importance of unmet psychological needs has emerged twice within this thesis within research conducted with haematological cancer survivors. The most common needs overall include fears about the cancer spreading and uncertainty about the future. Fear of recurrence is well known to be a common and significant concern for cancer patients, both during and well after their treatment has ended (Simard et al., 2013). Again, this draws parallels with previous work outlined within this thesis (both the systematic review and the qualitative study), fear of recurrence was highlighted as a key need for patients. Fear of recurrence was not rated as highly in Chapter 4 where the unmet needs of newly diagnoses patients were assessed: this is perhaps indicative of information needs and anxiety about

the immediate future taking priority at the time of diagnosis, and fears relating to cancer recurrence becoming more prominent as the initial cancer treatment draws to a close. This reflects existing research across wider cancer samples (Rogers et al., 2008) whereby fear of recurrence can become so intrusive into a patients thoughts after initial treatment, that special effort to address patient fears has been undertaken within the clinic setting.

Results indicated that both anxiety and depression within this sample are above the point-prevalence rates found within the general population (Baxter et al., 2013; Office for National Statistics, 2013), tying in with the previous point that psychological needs were felt strongly within this patient group. Levels of anxiety and depression were high even when compared to similar studies conducted in broader cancer samples (Armes et al., 2009; Carroll et al., 2003; Stark et al., 2002), yet similar levels have previously been found in haematological samples (Molassiotis et al., 2011). This suggests that distress in haematological cancer patients is high in comparison to other cancer diagnoses. The findings also highlight a discrepancy between the levels of distress found within the sample (between the HADS score and responses on the unmet needs questionnaire) and those expressing a desire for help via their unmet needs assessment. This finding is consistent with previous findings: not all of those who experience psychological distress want help to manage their concerns, indeed previous research has indicated that of those patient who experience both cancer and depression, only 36% wanted professional help to improve their psychological wellbeing (Baker-Glenn et al., 2011). This finding highlights the clinical utility of an unmet needs assessment. Instead of highlighting areas where patients may benefit from further support, an unmet needs assessment does this in addition to providing an indication of where the patient themselves would like to receive that support, thus helping to ensure that resources are allocated to both the area of greatest need but also where they are most likely to be accepted by the patient. It remains important however that clinicians are aware of the on-going potential for distress in patients who do not report a desire for formal support at that time. The findings from this study indicate that psychological concerns continue into survivorship and that unmet need does not need to be in the psychological domain in order to have a negative impact on psychological wellbeing. There is a need for support in cancer survivors that is not currently being met by current service provision or policy. A patient's active desire for further support may change as a patient's adjustment process evolves and the absence of formal support at the higher levels of the stepped-care model (National Institute for Health and Clinical

Excellence CSGSP, 2004; Moorey, 2013) does not mean that a patient would not benefit from on-going support from their current healthcare team.

In the previous quantitative study of newly diagnosed patients (Chapter 4), there were significant differences in unmet need, depression and QoL between the watch and wait and active treatment sub-groups. This finding was not observed in the current sample. This may be reflective of the psychological impact of cancer diagnosis converging over time, minimising the effect of treatment on wellbeing. Conversely, this may be indicative of a recruitment bias resulting from the source of participants for this study, a concern that will be discussed further within limitations.

The relationship between unmet need and psychological wellbeing

Within the context of the wider psycho-oncology literature, anxiety and QoL are key areas of concern for cancer patients (Stark & House, 2000; Aaronsen et al., 1993). Anxiety levels have consistently been shown to be higher in cancer populations than rates of depression and needs assessment studies often reveal anxiety, and notably fears around recurrence, as dominant unmet needs for patients (Harrison et al., 2009; Lobb et al., 2009). This was also evidenced in the systematic review outlined in Chapter Two where fear of recurrence was the single most commonly identified unmet need.

The strongest correlations between an unmet need domain and outcome variables was the domain of psychological need. This concurs with the results of the study described in Chapter 5 where this same result was found in a sample of newly diagnosed haematological cancer patients, adding weight to the assertion that the assessment of unmet psychological need has high levels of clinical utility. If unmet needs are found in this area, the potential to also be indicative of overall psychological health means that need assessment carries a dual purpose for assessing clinicians. Not only can needs assessment provide a direct indication of where desire for support lies, but can also be used as an acceptable way of measuring psychological health. In cancer patient groups, as is the case in wider mental health populations, the presence of distress does not always equate to a desire for assistance (Baker-Glenn et al., 2011); a needs assessment is a measure of wellbeing that can have wider applicability in light of the findings presented within this thesis.

Looking more closely at the relationship between individual need items and outcomes in Table 6, it was highlighted that 30 out of 34 items were significantly correlated with all

outcome variables. This is in contrast to the findings in Chapter 4 where only seven items were found to correlate with anxiety, depression and quality of life, yet in general terms it can be concluded that unmet needs correlate with psychological wellbeing. In that study, five of the seven items that had a relationship with all outcomes specifies fell within the psychological domain, strengthening the assertion that unmet psychological needs were important for gaining a picture of more general psychological health. The current findings indicate a more general link between need and psychological wellbeing. As patients transition into the survivorship phase of their illness, the expectation is often that life will return to normal; where this done not happen and unmet needs remain as the aftermath of illness, they continue to impact upon psychological wellbeing (Lobb et al., 2009). Almost all needs were found to correlate with all outcomes, implying that the presence of an unmet need, regardless of type, has the potential to have a negative impact on wellbeing and QoL in cancer survivors.

The Role of Psychological Flexibility

The results of the moderation analysis that investigated the role of psychological flexibility in the relationship between unmet need and wellbeing were somewhat surprising, in fact being in direct contrast to the original hypothesis. It was hypothesised that psychological flexibility would act as a buffer between unmet need and psychological wellbeing, reducing the negative impact of the presence of unmet need. Instead, the results indicated that the relationship between unmet need and psychological wellbeing was only present in those participant with average or above average levels of psychological flexibility for the sample.

The results indicate a division in the way in which unmet needs are experienced between those patients with low psychological flexibility and those with high psychological flexibility. The fact that the relationship between unmet need and outcome only emerges where psychological flexibility is at average or above average levels could be an indication that people who are more psychologically flexible are also more insightful generally into their cancer experience and the psychological impact of their disease. Psychological flexibility is a key component of ACT, an intervention with six key components: acceptance; mindfulness; values; committed action; observing the self; and cognitive defusion (Hayes, 2006). Considering each of these components individually may help to contextualise the findings of the moderation analysis. Mindfulness implies an awareness of the present moment and of one's own thoughts and feelings within that moment (Kabat-Zinn, 2003), acceptance implies an ability to allow thoughts to be present without struggling with them

(Hayes, 2006). If we assume that the six components of ACT are linked (Hayes, 2006) and that those participants who are more psychologically flexible are also more mindful, then it is plausible that this group of patients are those who are more likely to show an awareness of their unmet needs and to therefore report them on an assessment tool. Looking at the values component of ACT, this relates to people living in line with a set of values that reflect the things that are truly most important to them. Again, if those who are more psychologically flexible are more insightful into their own value systems, they are more likely to be aware of how a diagnosis of cancer has impacted upon their life and values, in turn creating an awareness of their own unmet needs. Observation of the self, or observing the self within a wider context may relate to participants with higher levels of psychological flexibility being more able to separate their needs and thoughts from their core view of themselves. Therefore, the presence of unmet needs can be viewed as a product of the situation rather than as an inner failing, making them more acceptable and more likely to be reported in the context of a needs assessment. In short, those who are more psychologically flexible may be more insightful into their own unmet needs and are therefore more likely to report the presence of unmet need or psychological distress. If people are psychologically inflexible, they may be less likely to be aware of or to acknowledge the impact of their diagnosis or be sufficiently aware of their own life values to have an awareness of how cancer has created a rift between their desired and actual states.

These findings must be treated with some caution, indeed a significant moderation effect was not found in all interactions that were tested. Looking more closely at where moderation was found to occur, psychological flexibility was found to moderate the relationships between: psychological need and QoL; sexual need and Qol; and patient care and support needs and both anxiety and QoL. Given that the findings fell outside of the original hypothesis, potential explanations for this deviation will be explored.

Given the areas of unmet need that were found to be significant within the moderation analyses, it is possible that the findings in fact are indicative of a methodological problem when using self-report measures. For example, the reliability of reporting of unmet sexual needs has long been queried (Schroder et al., 2003; Fenton et al., 2000): the social context of having sexual needs has the potential to affect the accuracy with which such needs are reported. Given that there is somewhat of a floor effect in unmet sexual needs in this sample, this explanation seems plausible.

It was possible that the measure of psychological flexibility chosen is not measuring this construct as expected within the sample, causing the unexpected results. It was considered whether the measure was, in fact, detecting the level of insight of need in the sample, that is where participants scored highly on the measure were those who were more insightful into their diagnosis and its impact. Yet the correlations between psychological flexibility and unmet need, anxiety, depression and QoL are as would be expected in light of the existing literature (Masuda & Tully, 2013; Ciarrochi et al., 2010); Cronbach's alpha was also within the acceptable range for all measures. Significant positive correlation was found between psychological flexibility and QoL with significant negative correlations between psychological flexibility and unmet need, anxiety and depression: together indicating that increased psychological flexibility is associated with better overall psychological health. Given this earlier finding, it seems unlikely that the measure of psychological flexibility, the AAQ II, is in some way causing the unexpected moderation findings.

In addition, not all unmet need assessments structure their measures in the same way and therefore the way in which we label this precise relationship may be dependent upon the measure used. For example, the CaSUN (Hodgkinson et al., 2007), another widely used and respected needs assessment tool does not include a sub-scale of psychological need or of support needs but rather has domains that include quality of life, emotional and relationship issues and the impact that cancer has had on your life perspective. With regards to the needs assessment tool used, the SCNS SF-34, it is perhaps unsurprising that unmet psychological needs were found to correlate with psychological outcomes, yet psychological flexibility was only found to be influential in the relationship between unmet psychological need and QoL, and not for either anxiety or depression. Given that the moderation analysis indicated that the relationship between unmet need and QoL as affected by the person's psychological flexibility, it is possible that where the relationship between unmet psychological need and both anxiety and depression is pre-existing, then it is more resistant to being affected by other factors than the relationship between need and QoL. Given the small sample on which these findings were based and the somewhat unexpected nature of the results however, the role that psychological flexibility plays in the relationship between need and outcomes requires further exploration.

Alternatively, it is possible that people with low psychological flexibility are also the group who are least likely to report the presence of unmet need. As an example, the items 'I'm

afraid of my feelings' and 'It's ok if I remember something unpleasant' are both included on the AAQ II as a measure of psychological flexibility. It is possible that a sub-group of respondents who score low on this measure are doing so because they are unwilling to acknowledge the difficulties associated with a cancer diagnosis and are therefore also unwilling to acknowledge the presence of unmet need. For some, it may be that reporting the presence of any type of distress or perceived weakness after cancer diagnosis is uncomfortable. There is little in the existing literature that connects psychological inflexibility to unmet psychosocial needs, therefore it is not possible to draw comparisons with previous findings in cancer groups.

It is also possible that, given the socio-demographics of the sample, there is some characteristic of the sample which makes the reporting of certain areas of unmet need or psychological flexibility either biased or inaccurate in some way which would impact upon the results of the analysis. The sample was predominantly older and retired, an age group where sexual changes are occurring regardless of cancer diagnosis (Avis, 2000). This may act to confuse findings relating to sexual needs, alternatively it may mean that sexual changes are accepted and not associated as a need directly related to being a cancer survivor. Within the qualitative study outlined in Chapter 3, unmet sexual needs were not raised as being a key issue for participants, rather they were seen as being of secondary importance to the physical and practical implications of a cancer diagnosis. Healthcare professionals can focus on the combatting of disease or make the assumption that sexual needs are not relevant to older adults, and the sexual implications can therefore be under-estimated and under acknowledged (Hordern & Street, 2007). Within this environment, patients can feel uncomfortable raising their concerns and the perception that only the physical or 'medical' aspects of cancer warrant further support is developed. In turn, the perception that sexual needs are less valid than physical needs may be in part creating the floor effect observed when examining the data range for unmet sexual needs.

Further research is needed to address these hypothetical explanations: until this time, no conclusive statements can be made with regards to why the findings were not as expected. What does seem clear is that psychological flexibility does have the potential to interact in the relationship between unmet needs and psychological wellbeing. The results of the correlation analysis highlight the relationship between psychological flexibility and psychological wellbeing in line with the existing evidence base (Fledderus et al., 2013; Ciarrochi et al., 2010; Hulbert-Williams et al., 2014) and significant results were found in

the moderation analysis. The fact that the nature of the moderation analysis finding were unexpected highlights the need for further research into the ways in which psychological flexibility interacts with an affects our psychological health: for this purpose, cohort designs would be more appropriate. A thorough understanding of this is essential in order to be able to develop research into clinically applicable interventions that will hold real benefits for patients. Without this knowledge, intervention development cannot be optimally efficient or the effects on patients fully understood.

Whilst psychological flexibility was found to moderate specific relationships between unmet need and both anxiety and QoL, in no cases was a significant moderation found where depression was the outcome variable. It has been proposed that psychological inflexibility may act as a risk factor for psychological difficulties, including depression (Biglan et al., 2008; Ciarrochi et al., 2010). The presence of psychological inflexibility has also been found to predict depressive symptoms in a community sample (Shallcross et al., 2010), together feeding into the hypothesis that those who are depressed are also more likely to be psychologically inflexible. From the correlations in this data, psychological flexibility and depression were strongly negatively correlated, supporting the theory that low flexibility and high depression are related. For all of the moderation interactions that were found to be significant, the relationship between unmet need and outcome only emerged where levels of psychological flexibility were average or above average. It is possible therefore that those participants who fulfil this criteria were also those participants who were least likely to display symptoms of depression given that depression has been found to be associated with low psychological flexibility. The group of participants for whom the relationship between unmet need and outcome was found to be present are not necessarily the group who are most likely to display signs of depression, providing a possible explanation as to why the interaction between unmet need and depression was not significant. If higher levels of flexibility is where the relationship between unmet need and psychological wellbeing, then in cases where low flexibility is present, these participants are also most likely to be depressed and psychological flexibility does not function as a moderator at this level.

Limitations

A major limitation of this work was the small sample size, notably of some of the rarer types of haematological cancers including the leukaemias and myeloma. While the sample is representative of the haematological cancer population where NHL, myeloma and CLL

are the most commonly diagnosed conditions (Public Health England, 2014), it does mean that the influence of the participants with CML and AML on the overall sample outcomes may not have as large an impact on the results as the more common diagnoses. However, given that that analysis was powered, this was not an overt cause for concern.

As the sample was recruited based on patient self-reports of whether they met the inclusion criteria, it was not possible to confirm the clinical demographics of the sample. It was also not possible to provide any follow-up support to patients who scored highly on the measures for anxiety and depression as is often the case in a sample recruited from within a clinical setting given that the nature of recruitment meant that the usual ethical safeguards were not possible. A more worrying implication is that this highlights the presence of a sub-group of cancer survivors who would benefit from ongoing support, yet the current provision of support services means that their concerns are not routinely picked up.

Recruiting a sample via online blogs and newsletters that are published by relevant cancer charities brings a potential bias to the sample. This was a self-selecting sample who were all engaged in some way with the charities prior to participation. They could, therefore, be viewed as either seeking support from their contact with the charities or who were sufficiently well psychologically adjusted to their diagnosis that they are able to confront their diagnosis by engaging with charities that provide support to people like themselves. Previous literature has demonstrated that patients who are more anxious or depressed are likely to be less engaged generally with their treatment, are less motivated, and less able to cope with the diagnosis (Hemingway, 1999). However, the relatively high levels of anxiety within the sample do not indicate that only the well-adjusted took part, prevalence rates such as the ones presented here goes somewhat against the perception that only the psychologically-well are willing to take part in research. It may be the case therefore, that those who do engage with cancer charities may be more likely to be anxious or feel a need for additional information than those who do not seek out newsletters or blog posts online, a potential explanation for why anxiety levels were so high within the sample.

Implications for interventions

The ultimate aim of exploring the role of psychological flexibility in cancer patients is to better understand whether the concept could be utilised as a way of reducing distress within this patient group. The findings from this work do point to the involvement of psychological flexibility in the presence of distress in haematological cancer patients, yet,

given the results of the moderation analysis, the findings are not conclusive. The correlation analysis does imply a link between psychological flexibility and psychological wellbeing, yet the way in which this relationship functions requires further investigation.

The findings of the moderation analysis highlight that, for one sub-group of patients, psychological flexibility may be linked to higher levels of insight into their own needs and wellbeing. This explains why understanding patient need is so relevant and important within the clinical setting. It does however, raise concerns that, for the sub-group of patients who are not psychologically flexible, an intervention that aims to increase flexibility may in fact also increase distress. If those with low psychological flexibility display less insight into their unmet needs and the psychological impact of their cancer, then acting to increase their flexibility may also increase their awareness of their unmet needs. If this were to be the case, we know that from the correlation analysis that higher levels of unmet need correlate with higher levels of distress; therefore, making these patients more aware of their unmet needs may also increase their related levels of distress, clearly not a desired impact of an intervention to reduce distress. However, were the intervention to be ACT-based rather than centred solely on psychological flexibility, then the potentially negative impact of increasing psychological flexibility is likely to be tempered by the other skills taught within an ACT programme. ACT is not just about psychological flexibility, but also encompasses teachings around acceptance and coping skills (Hayes et al., 2006). Each individual element of ACT is conceptualised as a positive skill, rather than simply a way of avoiding distress. Therefore, aiming to increase psychological flexibility within the context of a broader ACT intervention may not be such a concern for patients with low flexibility. In other words, distress may be higher because of awareness of need, but offset by the coping skills also provided: rather than avoiding distress through unawareness, we could address needs and keep distress at a minimum. Further research is required however, that will broaden the findings of this study to assess wellbeing in cancer patients along with a broader range of ACT components to better understand their breakdown and impact within this patient group.

Conclusions

This study has highlighted the strong presence of a relationship between unmet need and psychological wellbeing in haematological cancer survivors, supporting earlier work within this thesis that highlighted this same relationship in newly diagnosed patients. Further research is needed to determine to what extent this relationship is also true of survivors of

other cancer diagnoses. If found to be so, there are implications for the way in which cancer patients are supported in the long-term as the results demonstrate that haematological cancer survivors have ongoing care needs that are not currently being met. Findings indicate the presence of psychological morbidity at a higher rate than is typically found in general populations and gives some insight into areas of unmet need for the patient group. This could be due to either: haematological cancer patients having higher levels of unmet need; or that due to the method of recruitment, only participants with high levels of need were accessed. While unmet needs relating to physical, practical or informational matters may decrease after treatment ceases, the physical burden of disease lessens and time spent in hospital decreases, the emotional impact of having had a life threatening diagnosis remains. At present, cancer survivors do not routinely receive on-going support from their treating hospital, nor would all patients wish for this, however, these findings indicate that this lack of support is leaving a sub-set of patients with psychological difficulties and unmet support needs that would benefit from further input from experienced cancer professionals.

Further research is needed to explore the role that psychological flexibility plays in the relationship between unmet need and distress in cancer patients, to determine the precise nature of the relationship and whether it exists in patient groups beyond haematological malignancies. This research suggests that psychological flexibility does impact upon distress in cancer patients, highlighting the potential clinical utility of interventions that target psychological flexibility, such as ACT, in reducing levels of distress, yet the moderation analysis generated results that were somewhat surprising and generating further questions around how psychological flexibility impacts upon distress in this patient group. Future research should seek to develop new interventions for cancer patients that are effective in their ability to reduce distress and that are based on this concept in line with acceptable models of support for cancer patients. If found to be effective, interventions that target psychological flexibility may be effective in reducing the aforementioned levels of distress that persist into survivorship for a sub-set of patients.

Chapter 6 – The Methodological Challenges Associated with Researching Rarer Cancers in the UK

Overview

Conducting psychosocial research with cancer patients is challenging. When conducting research with rarer patient groups, this challenge is exacerbated. The ability to recruit large numbers of patients with a rare diagnoses and to engage clinical staff, who are themselves extremely busy and who perhaps do not perceive psychosocial issues to be a priority, further compounds the issue. These were challenges faced in the research presented within this thesis. Indeed, in the work outlined in Chapter 5, difficulties encountered in recruitment resulted in the amendment of the original analysis plan and a scaling back of the methodologies employed. In encountering and attempting to overcome these difficulties, a series of reflections on the broader challenges of research with rare cancer within the field of psycho-oncology were generated. As a result, this thesis chapter will discuss key challenges to the field of psychosocial oncology and argue that it remains important that such research questions are addressed. Challenges, such as the ones encountered here, make generalising previous findings from the psychosocial oncology literature into rarer cancer groups difficult, resulting in a bias in the patients on which our assertions as a field are based. However, the work remains imperative and the questions asked valid ones. Psychosocial wellbeing in rarer cancer groups is a challenging research area but it is one that we must face as a discipline, moving forward with the aim of making high quality psychosocial care available for all.

Every Patient Matters

Despite the difficulties encountered when attempting to conduct psychosocial research with cancer patients, particularly those with rarer diagnoses, the work is important for evidence-based practice and to ensure that all patients, regardless of diagnosis or demographic variables, have equal access to high quality, evidence-based support services.

Unless problems are resolved, we are creating inequalities and discrimination within how able we are as a system to manage the psychosocial health of all cancer patients.

'Every patient matters' is a slogan commonly seen on NHS materials, indicating that all patients regardless of their illness or background deserve high quality care. While healthcare staff on the frontline work to achieve this aim, without a reliable evidence base that is grounded in high quality, relevant research, then building a picture of best practice is not always straightforward. Both government and healthcare services have cited high quality, patient-centred healthcare for all (NICE, 2004), yet within the field of psycho-oncology research, there are considerable disparities in the available evidence base that stem from the methodological challenges innate to the field. With cancer, there are many different sub-groups of diseases, each with their own unique challenges, but where small population numbers may be seen as prohibitive to large scale clinical trials of the kind that are held up as the 'gold standard' of research. While it may be true that recruiting large numbers of these rarer patient groups may require a more complex recruitment strategy, this should not preclude the undertaking of high quality research.

There is political support for this rhetoric: at their most recent world congress, the International Psycho-oncology Society (IPOS) put forward a statement placing psychosocial care as a human right. This declaration places dignity at the centre of human rights, following this with the belief that, for cancer patients, maintaining their dignity is best achieved by taking care of the patient as a whole person, inclusive of their psychological, social and emotional wellbeing. A lack of acknowledgement of the impact of cancer on these aspects of a patient's life is failing to acknowledge the presence of pain outside of the physical. The Multinational Association of Supportive Care in Cancer (MASCC) have also put forward a position statement that places psychosocial care as integral to supportive care for cancer patients (Surbone et al., 2009). They argue for a paradigm shift in how supportive cancer care is conceptualised globally to recognise the importance of psychosocial concerns, cultural differences and spirituality within routine cancer care. The Cancer Reform Strategy (2007) acknowledged that a lack of information and an incomplete evidence base presents a major challenge in the reduction of inequalities within cancer care. From this, the National Cancer Equality Initiative (NCEI) was born. A report published by the group in 2010 (NCEI, 2010) stated that a future step for promoting equality in cancer care was that every patient should have access to a "high quality experience of their treatment and care" (page 27). This was the first step of their

recommendations listed, firmly placing importance of the patient experience as paramount.

The Importance and the Challenges of Psychosocial Oncology Research

This thesis has demonstrated an important theoretical contribution to knowledge with regards to the application of unmet needs within the broader context of psychological health; a concept with clear clinical implications for the management of psychological wellbeing in the clinical setting. More broadly, psychosocial oncology research tells us about the patient experience, something that has increasingly been recognised within the political and media discourse around cancer. Psycho-oncology is concerned with the psychological, social, behavioural and ethical aspects of cancer. For patients, it is the everyday impact of their disease that is most distressing, the deviation away from normality as a result of cancer (Diaz et al., 2008). While finding a cure for cancer is undeniably important and research into the biomedical aspects of cancer vital, until such a time when a cure is found, patients must continue to live with, and beyond, the disease. Understanding how patients experience cancer and what their support needs are allows us to tailor appropriate services that best meet these needs. Having appropriate support services in place ultimately reduces healthcare system burden: people who are more psychologically healthy are also more likely to be motivated, to adhere to treatment, to attend their appointments (Hemingway & Marmot, 1999), all of which cumulatively improve patient outcomes and have an associated cost benefit due to a less complex treatment pathway. Getting appropriate psychosocial care right from the beginning of the cancer experience also has an associated cost benefit. Keeping patients psychologically healthy and feeling supported reduces the number of patients who will later require more specialised psychological or psychiatric input; these are expensive services and services that cannot be made available to all due to cost and service provision.

As a field, psychosocial oncology has become overly focussed on research that relates to those who are easiest to recruit: namely white, middle-class women. When considering the difficulties in recruiting cancer patients into research, it makes sense that the most commonly occurring cancers are those that are best represented within the literature. Breast, lung, colorectal and prostate cancers are the most common cancers in the UK

today, together accounting for 46% of all deaths by cancer in the UK (CRUK, 2014). The number of patients diagnosed with these four diseases means that researchers are more likely to recruit larger samples from fewer sites in a shorter time frame. Within psycho-oncology, however, research relating to breast cancer has dominated to the expense of other diagnoses. A systematic review of research relating to cancer care found that one third of all existing research related to breast cancer (Bryant et al., 2014). A second review examining the evidence base relating to cancer survivorship also found a predominance of research relating to breast cancer (Richardson et al., 2011). While there is undeniable merit in researching the disease that is the biggest cancer killer of women in the UK, it does mean that a significant portion of our understanding of the psychological and social impact of cancer diagnosis relates to women and to women of a specific socio-demographic background. Outside of breast cancer, it is in fact men who are more likely to be diagnosed and subsequently die from the disease (Ferlay et al., 2010), a statistic that is especially true of the haematological malignancies included within this thesis. This highlights the real need to broaden our understanding beyond the realms of the most common and easiest to recruit in order to prevent gaps in the literature from widening. Challenges in recruitment must not mean that rarer patient groups, or indeed patient demographic groups that are harder to recruit into research, do not receive a proportional degree of attention within the relevant body of literature.

The dominance of certain cancers within the literature is paralleled in how the funding for cancer research is allocated. The published literature reflects the fact that a majority of the funding for cancer research is spent on breast, lung, colorectal and prostate cancers. In the United States, the National Cancer Institute released spending figures for 2012 that indicated that together the four most common cancer received $1438.7 million (National Cancer Institute, 2013). As a comparison, bladder cancer, melanoma, NHL, uterine, kidney and thyroid cancers received a combined spend of $348.7 million, less than one quarter of what was spent on the four common cancers. While it is reasonable that the most common cancers and those with the highest associated mortality rates receive an appropriate portion of the total spend, it cannot be forgotten that cancer is not one disease. Gaining knowledge of one condition, whether biomedical knowledge or psychosocial, does not always translate through to other cancer diagnoses.

In the UK, a major survey highlighted that spending on cancers can vary significantly, even where mortality rates are similar (CRUK, 2011). Of the haematological cancers, NHL and leukaemia fare well with the percentage spending associated with the diseases exceeding

the percentage of deaths attributable to each. In the cases of bladder, stomach, oesophageal and pancreatic cancers however, there is a higher percentage of deaths associated with each condition than the related amount of money spent. Looking at brain cancer as one example, they are the cause of the highest number of cancer related deaths in children, in under 25s and in under 35s (Brain Tumour Research, 2013). Of those diagnosed with a brain tumour, 58% die within a year. Despite this, between 2002 and 2012, brain cancers received 0.8% of NCRI spending (NCRI, 2014), a clear disparity between spending and the impact of the disease.

Looking at cancer research funding more generally, cancer prevention and control receives surprisingly little in both the UK and the US. In the longer term, cancer prevention is key to decreasing the incidence of the disease yet an NCRI report on spending on the less common cancers revealed that nothing had been spent in this area (NCRI, 2012). This report did indicate that, of the less common cancers, haematological malignancies did fare better than others in terms of money spent on research, receiving 41.8% of the money spent on researching rarer cancer groups.

Psychosocial oncology research is an area that typically does not fare well in comparison to the amount of money spent on biomedical cancer research. The precise amount spent on research of this type is difficult to determine, yet indications suggest that it makes up approximately 2% of the total spend (NCRI, 2011). This translates into there being substantially less research relating to QoL in cancer than there is biomedical research, despite evidence that patients value psychosocial research (Paul et al., 2011; Clinton-McHarg, 2010). A review of QoL literature however, found that while there is less QoL research within the cancer literature, research within this area is showing the greatest relative increase (Sanson-Fisher et al., 2010), highlighting the increasing recognition that high quality cancer care encompasses the whole person, not just their disease. In addition, this review found that while a majority of QoL research was still conducted with breast cancer samples, it was in fact studies with prostate cancer that were showing the biggest increase. While prostate cancer is still one the four most common cancers and already received a fair degree of attention within the literature, this does represent a shift in research priorities and a recognition that a wider variety of patient groups are deserving of consideration with the psycho-oncology literature.

A collaboration between over 100 international experts in the field of cancer research into current gaps in breast cancer research highlighted that there are major gaps relating to

both interventions and support for cancer survivors and in implementing sustainable lifestyle changes (Eccles et al., 2013). Given that only around 2% of cancer research funding goes into psychosocial research, addressing critical gaps such as this is a real challenge for the discipline as a whole. There has been an increasing recognition that patient priorities for research are important and need to be taken into account when allocating funds and developing research strategies (Steward, Caird, Oliver & Oliver, 2010). When patient views are taken into account, the emerging research agenda is one that is better suited to meet patient needs given that it was developed with them in mind. Research that has examined patient priorities when it comes to cancer research has repeatedly highlighted the perceived value of psychosocial research. Indeed the recent literature appears to indicate an on-going paradigm shift from professionally to consumer-driven research (Paul, Sanson-Fisher & Carey, 2013). While both viewpoints are representative of important voices within the literature, it must be recognised that patients themselves have rated the emotional, social and practical elements of living with cancer as being worthy of receiving more funding that is currently the case (Corner et al., 2007). In haematology in particular, this issue has been emphasised repeatedly with both adults, adolescent and young adults endorsing psychosocial research (Paul et al., 2011; Clinton-McHarg, 2010). While finding a cure or developing new treatments is deemed important by patients, for those already diagnosed it is the everyday impact of cancer that causes the greatest impact and learning how to live with their disease is a key priority.

There is a culture of evidence-based research and practice currently driving healthcare practice in the UK. A bias in how research is funded, however, creates an on-going bias in future research, in that it becomes easier to obtain future funding for projects that have an evidence-based rationale behind them. In order to be able to demonstrate both efficacy and patient acceptability of proposed interventions, high quality research is required on which to base the design. Indeed, a critique of the existing psycho-oncology literature is that it has been described as being descriptive in nature rather than seeking to pursue new interventions that may act to reduce the current gaps between research and clinical practice (Bryant et al., 2014).

Looking more specifically at needs research, we know from previous studies that unmet needs differ according to age, gender, personal history and cultural factors (Hodgkinson et al., 2007; Puts et al., 2012). This highlights the importance of assessing unmet need across a diverse range of patients. While research conducted with white, middle-class female samples is of value, it is likely to be limited in how widely it can be generalised across wider

diagnostic, cultural or age groups. Previous research has provided the field with an excellent grounding of some of the key issues and areas of concern for cancer patients, yet now we must move forward and explore the extent to which these findings are applicable across these wider patient groups, a notion supported by the finding within this thesis that haematology patients experience unmet needs in similar areas to solid tumour patients. Haematological cancer research has predominantly centred on the biomedical and treatment-based, the psychological aspect of living with these diagnoses have not been well covered within the literature and there has been a resulting gap in the evidence base with regards to their psychosocial needs and ultimately how this patient group can best be supported.

While recruitment and respondent bias continues to be a concern, it should also be acknowledged that psychosocial oncology as a sub-discipline of cancer research is increasingly attempting to lead the way in conducting research that is inclusive of all patients. There has been an increasing attention within the literature of aging populations (Thewes et al., 2004), of cancer patients whose first language is not English (Ayanian et al., 2005) or who are in some way a marginalised group such as those with cognitive difficulties (Allen & Mor, 1997) or those who are from an ethnic minority (Moadel et al., 2007). The challenges experienced during the research outlined within this thesis were ultimately borne out of the fact that this work was trying to achieve this in another underserved cancer group: the haematological malignancies. Given the current challenges within the wider field of cancer research, these problems are perhaps unsurprising.

Overcoming Challenges as a Discipline

The disparities in the existing evidence base and the difficulties in availability of research funding translate into real barriers to conducting psychosocial oncology research. Challenges that have been evident both within this thesis and across the wider field. These problems must be resolved in order for the discipline to progress; yet for progress to occur, there must first be a clear understanding of what the difficulties are to be overcome.

There may be a connection between research funding and the difficulty that psycho-oncology researchers can face in the initial engagement of healthcare professionals. In order for a project to be successful, funding bodies, recruitment sites, staff members and finally patients must be engaged and invested in the research. Past research that has

explored the acceptability of taking part in research during incredibly difficult times has indicated that participants can find engaging in research to be helpful (Gysels, Shipman, & Higginson 2008a; Gysels, Shipman, & Higginson 2008b). A study that interviewed bereaved relatives of cancer patients, a group that are renowned for being an ethically sensitive population for research engagement, found that many felt that taking part in research was helpful to them, even in cases where taking part had been difficult (Koffman et al., 2012). The often sensitive nature of the research and the perceived vulnerability of participant groups can lead to gatekeeping by both clinicians and family members, effectively limiting access to certain groups (Schofield et al., 2008), in extreme cases limiting the viability of projects. It may be that, given the lack of support for psychosocial research from the funding bodies, there is a filtering affect whereby clinician support for this research is impacted and the research not viewed as a priority. Given the already small population sizes of some of the rarer cancer groups, an inability to engage relevant sites or, once recruitment is underway, to gain access to eligible patients can hinder an already difficult recruitment process. While the work contained within this PhD was successful in terms of engaging multiple recruitment sites, clinician gatekeeping is always a concern. Given the known difficulty with clinician gatekeeping, building successful professional relationships with the clinicians working at each of the recruitment sites was a key challenge for this PhD. Recruiting participants in person not only enabled participants to discuss the study directly with the researcher, but also meant that the researcher could engage directly with clinicians, building a rapport and ensuring that the aims of the study were well understood.

Once clinicians are engaged in the projects and sites have agreed to take part, the next potential pitfall in psychosocial oncology research is engaging participants. The nature of the research typically engenders the need to engage patients at a highly stressful time of their lives. A cancer diagnosis is typically accompanied by large amounts of new information about the diagnosis, treatment pathways, clinical trials and what life will look like for the patient's immediate future. This is also likely to come during a time of high emotion, where the patient has had to endure the shock and distress of a cancer diagnosis and a shift in their expectations of what their life will look like. Attempting to engage patients into psychosocial research at this time point can be incredibly difficult. In addition to clinician gatekeeping, familial gatekeeping can also be problematic. In the case of this particular work, there is no way of knowing whether familial gatekeeping was problematic for recruitment, but as all participants were allowed to take study information home with them to discuss with family and friends as they saw fit, it is possible that this contributed in

some way to the overall response rates of the studies. For many patients, they have simply already had enough new information and change within their lives to contemplate taking on further disruption in the form of taking part in a research project. For many patients, taking part in this type of research will be yet another new experience at a time when most patients desire stability and a sense of normality (Ekman et al., 2004). There will also be a sub-set of patients who cope with their diagnosis by using avoidant coping strategies (Stanton et al., 2002), while these participants will be of great interest to the psychosocial researcher, they are also likely to be the group of patients least likely to engage in research that might force them to confront the thoughts and emotions relating to their diagnosis that they have been seeking to avoid. While there is likely to always be a sub-group of patients for whom engaging in psychosocial research is deemed to be too distressing and so decline to participant, for others, the unfamiliarity of this type of research may be the key issue. There is less publicity and awareness of cancer research that exists outside of the biomedical. This problem occurs in direct relation to the degree of funding that is awarded to psychosocial research. Psychosocial research has not been made a priority within cancer research, and until this happens, then public awareness is unlikely to increase. With an increase in public awareness will come an acceptance that taking part in psychosocial research is an integral part of the cancer experience, much in the way that there is an awareness of clinical trials and the potential benefits to patients. If psychosocial research becomes better integrated into routine practice along with the biomedical research, then it will become more acceptable to all parties. Clinicians will be more likely to be supportive and this will be passed on to patients who are known to follow the recommendations of their treating clinicians. Improving the patient experience and increasing the level of supportive care available has been on the political and healthcare agendas for over a decade in the UK (NICE, 2004), yet there has yet to be a full uptake of such recommendations. There is a gap between the mandates of governing bodies and the uptake of these directives within the clinical setting. Again, this comes back to the perceived importance of psychosocial research. Despite repeated recommendations for improved psychosocial care for patients, until this becomes a priority, the biomedical will continue to take precedence.

Of course, once patients are engaged as participants in a research project, the key issue becomes ensuring that they remain so. Follow up is notoriously difficult in psychosocial oncology research. Attrition is common, but is a real concern for the field due to its ability to threaten the validity of results (Bell, 2012). Given the nature of the people taking part in

research, attrition is perhaps unsurprising. While patients may agree to take part in a research study, once the physical impact of treatment becomes evident, many simply feel too ill to continue to take part (Applebaum et al., 2012). It must also be recognised that cancer is a life-threatening illness and that a sub-set of participants are likely to die during the study period, an issue within the study outlined in Chapter 5. Methods of improve attrition rates in such instances are difficult to identify: where the researcher must focus their attention is on retaining all participants who do remain alive and well enough to continue to take part in the study. Design of the study questionnaire, face to face recruitment and the engagement of the clinical team may all factor together to improve retention rates. Previous work that has looked at how to maintain engagement in research has found that ensuring a user-friendly and interesting questionnaire design (Edwards et al., 2002), questionnaire length (Dillman, 1993), the colour (Fox et al., 1988), being addressed to a specific person (Brennan, 1992) and the order of the questions included all affect response rates within questionnaire studies. In addition, the study having university sponsorship (Fox et al., 1988), reminders if follow up questionnaires are not received (Nakash et al., 2006; Brennan, 1992) and stating the benefit to society (Edwards et al., 2002) have also been found to improve response rates.

More broadly, there is an ethical concern inherent to psychosocial oncology research in that there is a risk that asking participants about their difficulties will increase levels of distress in those patients. The issue around participant burden can be contentious, yet previous research has demonstrated both that patients welcome research of this nature and has indicated ways to reduce potential burden (Pessin et al., 2008). Considering study design (Aaronsen, 1991) the length and structure of questionnaire or interview can be beneficial in reducing burden to participants (Pessin et al., 2008). A level of sensitivity to participant's needs and concerns is required to enable participation and this must be reflected in the research design (Gysels, Evans & Higginson, 2012). While the potential difficulties innate to the discussions around cancer and end-of life are undeniable, participants also report benefits from the social interaction, from the ability to make a contribution and to be able to talk about their illness and fears in a neutral environment (Pessin et al., 2008).

While there may be ethical concerns associated with psychosocial research, the evidence suggests that, when a research study is well designed with minimising the potential burden to participants in mind, this is often unjustified when patients' views are taken into account (Gysels et al., 2012). The implication therefore, is that psychosocial oncology as a research

field has to work hard to make sure that the ethical concerns are managed in such a way as to avoid becoming a perceived barrier in terms of both ethical committees and clinician gatekeeping. More pressingly, as a field there is the ethical concern that some patient groups are currently being under-represented within the literature and that, therefore, there is no evidence-base on which to base supportive care strategies for these patients.

Personal Challenges and Reflections

The challenges discussed during the course of this chapter are ones that impact upon the field of psycho-oncology as a whole, yet the personal challenges involved in undertaking a PhD and the reflections generated must also be acknowledged. Of the issues highlighted within this chapter, there were specific areas that represented particular challenges in the work contained within this thesis.

Moving chronologically through the process of conducting applied research, a series of difficulties were encountered. The initial hurdle, as is the case often in research of this kind, was in the accessing of new sites that were willing to host the project outlined in Chapters 3 and 4. This PhD project was co-funded by the local hospital, as such, it was possible to draw on the professional networks of those clinicians when attempting to recruit further sites. The development of a psychosocial oncology research group within the Psychology department also provided networking opportunities that provided new contacts for additional sites. However, it was still apparent that, compared to randomised controlled trials, psychological research was both less common and, as such, less well understood.

Once sites were recruited into the project, the next challenge was engaging individual clinicians who were the cornerstone of the recruitment strategy throughout this PhD. There was variability in which individuals were willing to support the project. Many were very generous with their time, for others, it was an additional time pressure where there was no perception of real benefit for the service. The variations in staff enthusiasm for the project may be, in part, due to perceptions of ownership of the study. The first hospital to become actively involved in the PhD project did so at a very early stage, indeed the Consultant Haematologist was involved in the proposal that secured the funding for the PhD. Once up and running, the nursing staff met with the PhD researcher within the first week of beginning the PhD to discuss their patient group and what they perceived the challenges and unmet needs to be for haematology patients. This was also the only hospital to be involved with both the qualitative and quantitative studies. This meant that

the clinical staff in that haematology department had a sense of ownership of the project and clearly had a desire to see research of this kind being undertaken. In the other three participating sites taking part in the study outlined in Chapter 4, this sense of ownership of the project, and perhaps the same level of interest in psychosocial work, could not have been present.

The biggest difficulty throughout this PhD has been in the recruitment of participants into studies, something that has been discussed previously in both Chapter 3 and Chapter 4. The time spent attempting to recruit new participants meant that this was not a project that could be completed within a short time frame. The importance of recruiting participants face to face, both in an attempt to boost recruitment and retention rates, but also because this was felt to be the most ethical way to approach patients, meant that the researcher needed to attend hospital clinics across four sites which took in excess of 20 hours per week for over a year. While this was an acceptable commitment within the bounds of a PhD project, it does make recruiting participants into psychosocial studies of rare cancers costly, a factor that may also influence funding decisions.

While a source of frustration, recruitment difficulties did, at least in part, lead to the development of the moderation study outlined in Chapter 5. The importance of the supervisory team and of having academic support became very clear and was invaluable at this time. When recruitment for the study in Chapter 4 was at its most challenging there was a real sense of discouragement, yet having supportive and enthusiastic supervisors not only helped to maintain morale, but also led to the generation of new ideas and the evolution of the PhD to include the moderation study that not only highlighted the presence of a relationship between need and distress but has clear applications for future interventions. Ultimately, including this study created a sense of completeness within this body of work, and is felt to have expanded and consolidated the contribution to knowledge that this thesis is able to make.

On reflection, experiencing challenges and difficulties during the data collection process has ultimately contributed to this researcher's academic development and provided a deeper understanding of what it is to conduct applied psychological research in the cancer setting. By experiencing challenges first hand, an awareness is developed with regards to how these might be met going forward, fostering a pragmatic outlook for future projects.

To conclude, if all patients are entitled to receive high quality healthcare in the UK, then this should hold true regardless of the population size of the patient group or the

psychosocial nature of the research. If the best care is evidence-based care, as has been so widely cited in recent years, then research must be as open and unbiased as the healthcare system which it serves.

Chapter 7 - Conclusion and Implications of the Research

Overview

This thesis aimed to identify the specific unmet supportive care needs that are most relevant to haematological cancer patients, and to explore the wider psychological impact of unmet need within this patient group via a series of research questions:

1. ***What is the current evidence base regarding the unmet psychosocial needs of haematological cancer patients and where do the gaps in our knowledge lie?***

2. ***What do haematological cancer patients perceive to be their key areas of psychosocial needs and why were those specific needs important during the patient experience of cancer?***

3. ***What are the unmet psychosocial needs and psychological outcomes of newly diagnosed patients and are these two concepts related?***

4. ***What are the long term psychosocial needs of haematological cancer survivors and does the concept of psychological flexibility mediate the relationship between need and psychological outcome?***

These individual research questions have been addressed and discussed throughout previous chapters of this thesis, but all ultimately come together to provide a better understanding of unmet need and psychological wellbeing in haematological cancer patients. Throughout this body of work, the relationship between unmet need and distress has been conceptualised and explored within haematological cancer patients. That there is a relationship is evident, and psychological flexibility has emerged as a potential moderator between the two. This final chapter will bring together these findings and conclusions to (a) outline the key findings to emerge from the research and (b) to explore the clinical and research implications of the work.

The Unmet Needs of Haematological Cancer Patients

The work contained within this thesis has expanded our understanding of both the type and prevalence of unmet psychosocial needs present in haematological cancer patients. This was explored as an on-going theme throughout this thesis, with each ensuing chapter

seeking to build and expand on the previous work. For the purposes of this thesis, an unmet psychosocial need was defined not only as a concern that related to a patient's physical, psychological or social wellbeing, but as the active desire for support or assistance in one of those areas. By this definition, an unmet need implies a gap between what is desired and what is reality for that patient. The first study described within this thesis, a systematic review of unmet need within haematological malignancies, sought to identify those needs within this patient group. The findings of this review confirmed the presence of unmet needs within haematological cancer patients, but also revealed a distinct lack of a comprehensive body of work on the topic. Only three studies were identified that specifically explored need within haematology groups (Lobb et al., 2009; Molassiotis et al., 2011; Hammond et al., 2008) and there was just one that included all diagnoses fitting under this umbrella term (Lobb et al., 2009). In identifying this evidence gap, the systematic review acted as a preparatory work for subsequent studies. Understanding unmet needs, or where the gap between patients' wishes for support and the current service provision lies, are essential in order for future service development to be in line with patient requirement and for such future development to focus on the areas that are currently inadequate or inaccessible for the intended patient group. In turn, understanding where patients want help and support is the first building block in developing support services and interventions that are both relevant to and acceptable to patients, in turn meaning that services are more likely to be used and to be efficient, minimising costs.

In response to the lack of existing literature found in the systematic review, the identification of unmet needs ran as a theme throughout the entirety of this thesis, being at the core of each study. Both quantitative questionnaire studies used the SCNS SF-34 to assess unmet need; this is considered a gold-standard tool that has been widely used within previous needs research (Bonevski et al., 2000; Sanson-Fisher et al., 2000) enabling direct comparisons between findings. In both studies (Chapters 4 and 5), there was a floor effect observed in that a significant sub-group of participants expressed no unmet need for individual items. Lack of energy/tiredness, not being able to do the things you used to, uncertainty about the future and concerns about the worries of those close to you were amongst the most highly rated unmet needs in both quantitative studies, suggesting that these are needs that are applicable throughout the cancer experience, transcending time-points and their associated implications. Learning to feel in control of your situation was also found to be highly applicable to newly diagnosed patients whereas anxiety and fears about the cancer spreading held a specific relevance to the cancer survivor sample. This

work also highlights that unmet needs are not just relevant to patients who are newly diagnosed or undergoing treatment, but that they persist into survivorship, a time when typically the level of ongoing support available to patients from their clinical care teams decreases dramatically.

The qualitative work within this thesis (Chapter 3) allowed for an expansion beyond quantitative identification of need into an evaluation of why needs are felt to be relevant and applicable to a patient group, and the barriers facing patients when attempting to access support for their unmet needs. This methodology complemented the quantitative work contained in this thesis as it used an alternative research approach to explore the identification of areas of unmet need, but it also provided an additional dimension and depth to this understanding, moving beyond the simplistic description of quantitative work. Identifying and understanding the specific barriers that prevent unmet needs from becoming met provides insights into areas where current service provision remains inadequate or ill-suited for the meeting of needs; this level of exploration was better suited to an interpretative qualitative methodology, hence the use of IPA. Participants in this study reported feeling unsure or unable to raise concerns that did not directly relate to their physical health; this was very much tied into the idea of the hospital being perceived as an environment that was primary concerned with medical, not psychologically supportive care. These findings highlight the importance of psychosocial issues being raised within the clinical consultation and the need for healthcare professionals to be aware of, and be comfortable raising, potential concerns rather than expecting patients to raise issues themselves. However, in order for this obstacle to be overcome in clinical practice, clinicians must both be aware of the type of unmet needs most common within their patients, and feel a sense of self-efficacy and confidence in their abilities when it comes to detecting and managing distress. While there are existing training programmes that aim to improve clinician skill in the detection and management of distress (Moorey et al., 2013), there is as yet no convincing evidence that such training translates into improved detection rates or improved patient experience (Moorey et al., 2013), although they do appear to improve clinician confidence.

In summary, this thesis adds to the existing body of research by addressing the unmet needs of haematological cancer patients across (a) multiple time points and (b) in patient sub-groups where there has previously been little focus within the scientific literature. Key areas of need have been identified that are of particular relevance to this patient group, yet common in all studies undertaking is the finding that there are similarities between the

types of unmet need experienced by haematological cancer patients and those patients who have a solid tumour diagnosis. Prior to this work, there was an expectation that the clinical differences between these two categories of cancer patient had the potential to translate into differences in the type of unmet need experienced, in much the same way as differences that result from other socio-demographic factors (Fielding et al., 2013; Harrison et al., 2009; Hubbard et al., 2014). This thesis has demonstrated that this is not necessarily the case, and that there are some key areas of need that are broadly applicable across all cancer groups: unmet needs relating to the physical and practical impact of cancer; to uncertainty and fears about the future; the emotional and psychological impact of disease; the need for appropriate and relevant information; and, the need to feel supported by both healthcare professionals and by those close to you are relevant to patients regardless of the type of cancer that they are diagnosed with. This novel finding has a real clinical significance both for how clinicians approach and manage unmet needs and for designing and implementing interventions that are designed to meet unmet needs. If unmet needs are broadly applicable, this suggests that interventions that aim to meet needs more generally will have a wide clinical utility. This discussion will now move on to explore three key messages that have emerged from this work, and have important implications; the finding that needs have broad applicability is particularly noteworthy within this context.

A real success of the work contained within this thesis has been the merging of different methodologies to produce a body of work that is both complementary in its findings and has an added depth in terms of how the data can be interpreted and understood. Each subsequent study design built on the previous work, cumulatively funnelling the research to narrow the focus of the work as it progressed. Within this thesis, there is work that confirms, expands and develops the theory of unmet need within cancer patients, a process that by necessity must be multi-dimensional and reactive to on-going development of knowledge.

Key Message 1: Haematological cancer patients do not identify as belonging to broader group of cancer patients

If unmet needs are broadly applicable across cancer groups, then it is plausible that interventions designed to combat unmet needs would be applicable to all cancer patients, as a comprehensive group. While the logic of this assumption is sound, the findings of the

empirical work in this thesis challenge this assumption and presents a rationale for why haematological cancer patients have been traditionally less likely to access certain supportive care services (Howell et al., 2013; Howell et al., 2011).

The qualitative element of this thesis in particular really contributed to the evidence base by articulating some of the specific challenges associated with being a haematology patient from the patient perspective: notably, the perceived differences between themselves and solid tumour patients. A key theme to emerge from the qualitative chapter (Chapter 3) was the participants' need to feel supported as a haematology patient and the barriers that are preventing patients from accessing support. Participants perceived their diagnosis to be poorly understood by both the general public and by some healthcare professionals; this was not believed to be the case for other cancers. But, perhaps more importantly, participants did not identify themselves as being cancer patients and this was evident in two distinct ways. First, a widely held belief within the sample was that they were haematology patients, or lymphoma patients: their self-identity was certainly not as a cancer patient. The perceived differences between haematological and other cancers affected participant's views of both how acceptable support services were and whether they felt comfortable accessing those support services when they are not a 'cancer' patient. Second, some patients simply did not wish to be associated with a 'disease label' at all, and the suggestion that they should adopt the label of 'cancer patient' was felt to be unreflective of who they believe themselves to be, and the self that they wish to portray to the world. If existing support services are designed for cancer patients, a group to whom participants did not feel a sense of belonging, then the applicability of such services is questioned. This disparity between haematological and solid cancers was one of the clearest messages from this qualitative work; whether this notion would be supported by healthcare professionals or service providers has not been explored within this body of work, but is certainly worthy of further research.

The question of whether patients with a haematological diagnosis should be classified under the umbrella of 'cancer' is an interesting one. Some of the chronic diagnoses included within this research (e.g. indolent NHL) were most notably perceived to fit less neatly into what the cancer experience is generally accepted to be. Haematology oncology departments are often physically separate from the oncology departments within hospitals, running separate clinics that are staffed primarily by haematologists rather than oncologists. The prognosis of these cancers and the treatment methods employed can differ from those seen in the solid tumours. Yet, haematology is still generally accepted as

being a sub-type of cancer, despite often sitting slightly apart. The difficulties that some patients have in identifying with the cancer label, feeling themselves instead to be a haematology patient, have been highlighted. On this basis, there is perhaps a case for a more formal differentiation between haematology and oncology, yet this does seem counter intuitive when considering the potential impact for patients. While the suitability of support services for haematology patients has been questioned within this thesis, it still remains that haematology patients are allowed access to cancer services such as those run by Macmillan, to support groups and to more formal support services available to cancer patients in accordance with best practice guidelines, even if they aren't currently choosing to use them. If this label were to be taken away, it seems likely that what support is available would only decrease. This brings the argument back to the previous paragraph, it seems likely that future work that aimed to make services more inclusive to the rarer cancer groups or less widely recognised groups, even if this merely represents a shift in perception, is what would have the most meaningful impact for patient support.

As reported elsewhere in this thesis (e.g. Chapters Four and Six), difficulties were experienced when attempting to recruit large numbers of patients whose diagnosis was both haematological and chronic. Difficulties in recruitment within the field of psychosocial oncology more generally may well be a compounding factor in the comparative lack of existing research in haematology; yet, as explored in Chapter Six, such difficulties do not mean that research undertaken with smaller patient groups is not valid, or that it cannot have meaningful contributions to both our theoretical understanding of the cancer experience and implications for clinical practice. What the research within this thesis has indicated is that unmet needs are present for haematological cancer patients, regardless of sub-diagnosis, treatment type or time point within the cancer experience, and that ultimately the presence of unmet need affects psychological health. While haematological cancer patients may number less than more common cancer groups, there are still important public health implications to be considered that result from the presence of unmet need to be taken into consideration. There is a significant body of research, for example, that implicates both psychological and social stresses with increased mortality, morbidity and worsened functional status, both for general health (e.g. Kiecot-Glaser et al., 2002) and cancer (Kroenke et al., 2006; Antoni & Lutgendorf, 2007) samples. By maintaining the psychosocial health of patients, healthcare services are by default also ensuring that patients cope with their illness better and that they manage their illness more effectively by being more likely to attend appointments and adhere to treatment

regimes, maintain a healthy diet and exercise, and monitor their on-going symptoms (Adler, 2008). Attending to patient need, therefore, has the ultimate benefit to healthcare services of reducing treatment-associated costs and reducing the costs related to a patient requiring formal psychiatric, psychological or social support.

The extent to which participants' perceptions regarding the applicability of existing support services to their concerns is grounded in reality is currently unknown. There is little existing research that reports on healthcare professional's perceptions of haematology patients and how they fit within a broader oncology remit. However, a recently published paper has explored at why haematology patients are less likely to access palliative care services (Wright & Forbes, 2014); these authors suggested that there are barriers to collaboration between haematology and palliative care staff, and it is possible that similar barriers exist elsewhere. While this thesis has presented barriers to accessing support from the patient's perspective, it may also be true that there are barriers between multi-disciplinary clinicians with regards to ease of referral between services (e.g. between haematology and psychological services) that is also impacting upon patient access to support. Further research is needed to both further explore the clinician perspective of how the haematology patient fits into the cancer care setting, and to determine to what extent these participant's perspectives are indicative of current service provision more broadly. Whether support services themselves need amending to better suit haematology patients or whether they simply need to better advertise themselves to seem more acceptable to wider numbers of patients is worthy of future attention. In general, the areas of need highlighted by participants within this thesis do not deviate significantly from what is already understood to be relevant to cancer patients which perhaps indicates that existing services would be suitable, and that it these perceptions of self-identity and suitability that need to be altered for optimal service delivery benefit.

Key Message 2: Unmet Needs Are Associated with Poorer Psychological Health

The findings reported in this thesis clearly illustrate the presence of a relationship between unmet need and psychological wellbeing; this is the first time that this has been fully explored and contextualised in a haematological cancer sample. A strong relationship between the presence of unmet needs and psychological outcomes such as anxiety,

depression and quality of life, was observed in both newly diagnosed patients (Chapter 4) and cancer survivors (Chapter 5). Across both studies, the correlation between unmet psychological needs and key outcomes were consistently the strongest observed, indicating that unmet psychological needs and psychological wellbeing are intrinsically related in this patient group. This is perhaps an intuitive findings: that where psychological need is present, psychological problems are more likely to occur. However, it still carries clinically predictive value in that holistic needs assessment has the potential to be utilised as a general indicator of overall psychological health.

Focussing on individual items, or specific needs, endorsed by patients and how these correlate with outcomes, there were some important differences observed between the newly diagnosed and survivors samples. In the newly diagnosed participant group, seven of the 34 items on the SCNS SF34 significantly correlate with all outcomes; five of these needs fell within the psychological domain. As newly diagnosed cancer patients, there is an expectation that there will be a physical impact of the illness and treatment, that work and everyday life may be affected, and that there will be a need for information about the diagnosis and what comes next. While there are needs present within these areas, the fact that they are perceived to be normal or to be expected meant that the presence of need in these areas did not impact negatively on overall psychological wellbeing As an overall need domains, the relationship between unmet physical need and psychological wellbeing was present, but this was less statistically strong at the individual need level than was observed for psychological needs. This may be because, while individual needs are manageable and indeed expected, as a group of needs the impact is greater; this finding confirms suggestions made by participants in the qualitative study (Chapter 3).

Conversely, in the sample of cancer survivors, a much higher number of individual needs items (30/34) were found to significantly correlate with anxiety, depression and quality of life. While unmet psychological needs still had the strongest correlation as a need domain, the presence of a higher number of individual needs was more psychological distressing than was the case for newly diagnosed patients. As cancer patients, the expectation is often that once treatment is completed and you become ‘cured’, and that life will then return to normal and the spectre of cancer will recede. In reality, however, this is often not the case and for many individuals the long-term side effects of treatment, the threat of cancer recurrence and the removal of the on-going support from the treating hospital remain common areas of concern for cancer survivors after treatment. This deviation from what was expected after the completion of treatment, may well be what creates the

negative psychological impact of on-going care needs. Continued unmet needs serve to remind survivors of what they wish to forget and put behind them, and to highlight that life has not quite returned to the normality that was so hoped for. Unmet needs do not have to fall within the psychological domain on the assessment tool to impact upon a patient's psychological and emotional wellbeing, nor is their presence confined to the diagnosis and treatment phases of cancer. Physical, practical or information-related needs all have the potential to have a psychological and emotional impact and their impact can continue into the survivorship phase of illness.

Significant differences in quality of life were also observed between newly diagnosed patients allocated to watch and wait and those receiving active treatment; this was not, however, found to be the case in the survivors' sample. This suggests that patients monitored via watch and wait have a better quality of life at the time of diagnosis but that this difference diminishes over time. This is logical: patients who are monitored via watch and wait immediately after diagnosis do not have to cope with the physical burden of treatment or the disruption of needing to attend hospital appointments on a regular basis. However, as time passes, the impact of living with uncertainty may become more impactful and this is likely compounded by the challenge of disease progression. It is worth noting that the inclusion criteria were widened for the survivor cohort, being more inclusive of a range of haematological malignancies. This may have impacted upon group means if we assume that different diagnoses will differ in their specific unmet needs and wellbeing. However, watch and wait is generally only utilised with patients with specific diagnoses, those included within newly diagnosed cohort, meaning that the impact of including more diagnoses is unlikely to have impacted upon the mean QoL of the watch and wait group.

Anxiety and depression can be very real concerns for cancer patients, yet this will only be the case for a minority of patients. While psychological morbidity can, and should, be detected and managed within the cancer setting, there is another, potentially much larger, sub-group of patients who do not reach clinical thresholds yet for whom distress is present, albeit at a sub-clinical level. Formal measures of anxiety or depression would not classify these patients are requiring assistance, yet often it is not so clear-cut with many patients with sub-clinical levels of distress benefitting from additional support: the presence of distress increases the likelihood that patients will go on to experience clinical co-morbidity which increases the burden of illness for both the patient and healthcare services. The presence of distress decreases treatment adherence and motivation (Manning & Bettencourt, 2011), with some studies indicating that overall prognosis can also be affected

(Pinquart & Duberstein, 2010). For healthcare services, there is a cost implication in that the average length of consultations is likely to rise (Stirling, Wilson & McConnachie, 2001) and, that in the longer term, additional support services are more likely to be utilised. Holistic needs assessment has been endorsed for use within the cancer setting in the UK (NICE, 2004) and the relationship between unmet need and psychological health means that an assessment of this type may be clinically useful in identifying those patients who want further support yet may not reach the clinical cut-off on a formal distress measure. The utilisation of needs assessment in this way may help to reduce burden to both patient and to services by allowing needs to be met before they escalate. The onus is placed on the clinician to be able to appropriately triage distress and to be able to appropriately refer patients on to more specialised services for further support. This approach complements the NICE (2004) recommendation of the use of a tiered approach to psychological care.

The relationship between unmet need and psychological wellbeing has implications for the clinical utility of needs assessment measures. Formal psychological support is not always desired by patients (Baker-Glenn et al., 2010), nor well signposted by clinicians. In light of the findings presented within this thesis, needs assessment takes on a new dimension as a more broad assessment tool for providing clinicians with an indication of the patient's overall psychological health. Patients can be theorised as falling within one of four quadrants (figure 1): (i) those who neither want nor need help; (ii) those who want help but do not need it; (iii) those who need help but do not want it; and (iv) those who both want and need help.

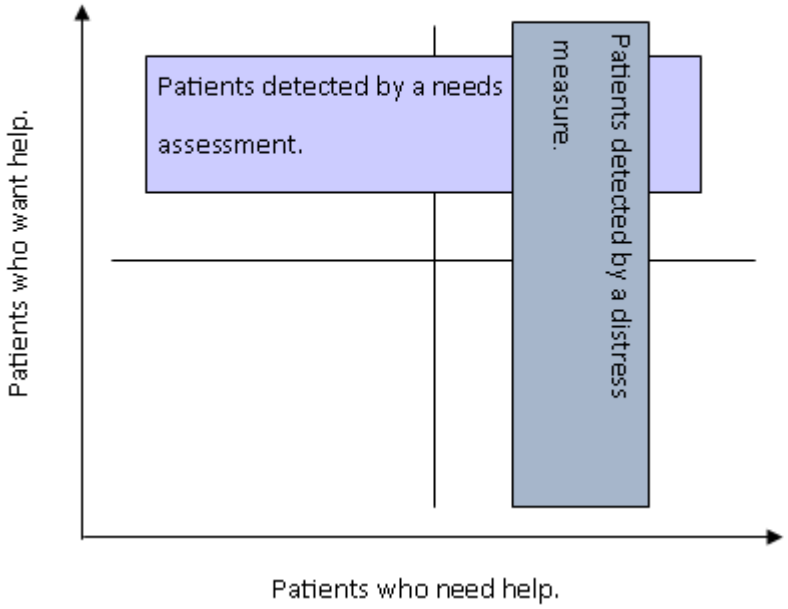

Figure 7.1: Diagram to illustrate the four quadrant of patients who want/need help.

Existing measures of distress highlight patients who fall within both of the latter two groups, yet when assessed in this way, there will be a sub-group of patients who may receive an assessment for a support service that they have not desire or intention of accessing. This is both unwanted and potentially distressing for the patient. Needs assessment allows healthcare professionals to determine which patients fall within either of the two groups of patients that desire help. The clinician must then make a decision with regards to what further support or referrals, if any, are appropriate for that patient. Peer support groups, group interventions and successful doctor-patient communication may all be appropriate forms of support for patients whose levels of distress are below that required for formal intervention from psychiatry or psychology colleagues, but who may benefit psychologically from support from other sources.

Given the role that psychological flexibility is thought to play in the maintenance of general psychological health (Fledderus et al., 2013), the finding within this thesis that psychological flexibility correlates strongly with unmet needs (Chapter 5) provides further support for the hypothesis that unmet need could act as a more general barometer of psychological health. An unmet needs assessment is not directly psychological in nature and, therefore, may prove to be more acceptable to a broader range of patients than psychological or psychiatric measures. It is also a more generic assessment tool which may

also act to improve uptake by general medical staff who do not always feel proficient in using a more specialist measure (Mitchell, Kaar, Coggan, & Herdman, 2008). The additional benefit of the premise of using needs assessment as a measure of psychological health is that there are already multiple directives from both policy makers (NICE, 2004; Department of Health, 2011) and cancer charities (Young et al., 2012) that state that needs assessment should be an integral part of cancer care for all patients. The fact that the evidence base and the policy makers have been commending the use of needs assessment for more than a decade should translate into a broad uptake within the clinical setting nationally, yet, this does not consistently seem to be the case. Clearly, there is further work to be done with regards to the routine uptake of needs assessment within the clinical setting and barriers to the implementation of such need investigating.

The work contained in this thesis highlights the importance of unmet need as a concept both within the scientific literature and within the clinical setting. This creates opportunities for both a deeper theoretical understanding of the presence of distress in cancer patients and how this arises, and for the development of interventions. Some cancer patients experience significant psychological distress and others do not, but the reasons behind this are not well understood. The insights provided within this thesis indicate that the presence of unmet need, a gap between what is real and what is desired with regards to a patient's supportive care, may, at least partially, provide an explanation for the distress that is present in a sub-group of patients. It is, therefore, likely that interventions that are designed to meet unmet need in cancer patients will display a broader clinical utility and will also act to improve the psychological wellbeing of patients more generally. In the current climate of limited healthcare resources, implementing supportive care measures that have the greatest clinical impact will always be of benefit.

Key Message 3: Psychological Flexibility Impacts upon the Relationship between Need and Wellbeing and Affects the Experience of Distress in Patients

The study of haematological cancer survivors (Chapter 5) demonstrated the relationship that is present between psychological flexibility, unmet needs and psychological wellbeing. Correlational analysis highlighted that higher levels of psychological flexibility relate to lower anxiety, depression, unmet need and higher quality of life; a finding that is consistent

with previous research that has linked psychological flexibility to better overall psychological health (Ciarrochi et al., 2010; Fledderus et al., 2013; Hayes et al., 2008). The discovery that the relationship between unmet need and psychological wellbeing is only present in people with higher levels of psychological flexibility was novel, and contributes to the current theoretical understanding of the presence of both unmet need and distress in cancer patients. This finding was somewhat surprising; the hypothesis explored was that high levels of psychological flexibility would buffer the impact of unmet need on psychological wellbeing, when, in fact, the data showed the opposite to be true. Considering the role of psychological flexibility within an acceptance and commitment framework (Hayes, 2004), however, potential explanations are to be found. According to this framework, we would expect that people who display higher levels of psychological flexibility are also more likely to be more mindful, demonstrating a deeper awareness of their unmet needs and an awareness of the impact of their cancer diagnosis than someone who is very psychologically inflexible. The increased reporting of unmet need in people who are more psychologically flexible may be in part due to a relationship between increased flexibility and mindfulness. These concepts are related to an increased awareness of one's own life values (Hayes et al., 2006), as such, the likelihood that someone will be more aware of how their diagnosis has created a gap between their current situation and how they would wish to live in line with their identified values, an unmet need, is increased. However, these findings also indicate that an intervention based around psychological flexibility must be approached with some caution. While psychological flexibility was found to be correlated with better psychological outcomes, it was also demonstrated that for the sub-group of patients who are psychologically inflexible, there are potential risks associated with attempting to change this. If increasing psychological flexibility will increase insight and awareness into the impact of a cancer diagnosis and unmet needs, then it is plausible that increasing psychological flexibility will also increase distress if people become more aware of the negative impact of their disease. Interventions must have a dual focus, therefore, providing distress reduction training, in combination with awareness-raising initiatives. This has particular relevance, for example, to the rise of mindfulness based interventions in the cancer setting: these interventions are very effective at improving awareness but place less emphasis on coping with distress.

The finding that psychological flexibility plays a role in moderating the presence of distress in cancer patients builds upon existing literature that places psychological flexibility as the active component of change in ACT (Fledderus et al., 2013). A recent review suggested that

ACT is a potentially important model for intervention in the cancer setting by virtue of psychological flexibility as its underlying framework (Hulbert-Williams, Storey & Kelly, 2014). In order for the eventual implementation of an intervention to become widespread, it must be both clinically effective (based upon sound empirical evidence) and cost-effective (given the limited resources available within healthcare). Conceptualising an intervention to improve psychological flexibility within an ACT framework counters the potential to increase distress in cancer patients: ACT also teaches coping skills and problem-solving (Hayes et al., 2006), mechanisms that give patients the skills to manage their psychological health.

Studies such as the one outlined in Chapter 5 strengthen the rationale for interventions that are intrinsically related to psychological flexibility, by demonstrating how the construct functions as an active component of change within the potential reduction of distress, and this has previously been highlighted as a priority for psychosocial oncology research (Stanton et al., 2012). Understanding where active change occurs and for whom an intervention is likely to be successful allows for interventions to be developed that specifically target this, therefore reducing elements that do not produce any psychological change or benefit. As a result, interventions can be developed that are honed and streamlined to these active elements, thus making them as effective as possible while containing only elements that will produce change. This also make them cost-effective. There has already been some exploration of ACT within cancer groups, with early research indicating that positive changes to wellbeing are observed (Hulbert-Williams et al., 2014). The next step is to determine both the feasibility and patient acceptability of implementing such interventions on a larger scale within the cancer setting.

Implications for Research

The findings contained within this thesis have multiple implications for research. The first key finding, that unmet needs appear to be broadly applicable across cancer groups is indicative of a *lack* of need for further descriptive needs-based research. Rather than continuing to explore type of prevalence of unmet need within discrete patient sub-groups, instead the psycho-oncology research community needs to look towards large scale, inclusive cohort studies that examine unmet need across cancer groups over time. This would confirm the finding of broad applicability of unmet need across cancer patients as an inclusive group and to determine how unmet needs evolve over time. The work contained

in Chapter 6 highlighted the difficulties in conducting large scale studies, particularly when attempting to recruit patients with a rare cancer diagnosis. However, as discussed within that chapter, difficulties at the practical level should not preclude attempts at creating high quality research that asks important questions about the cancer experience.

A deeper understanding is needed of how different cancer patient groups perceive themselves to sit within this broader group. Findings from within this thesis have highlighted the view held by haematology patients that they do not feel a sense of belonging with other cancer patients, rather believing themselves to be a distinct group. This had implications for the perceived acceptability of support services that were advertised as being for cancer patients. This is a novel finding, and the degree to which this might also be true of other cancer groups, particularly other rarer cancer groups, is not known. In addition, there is a lack of evidence that explores the perceptions of healthcare and service providers. Further qualitative work would allow for exploration of the views of additional stakeholders, healthcare professionals and service providers, to determine whether there are common beliefs held across different groups. If it transpires that the differences exist in patient perceptions only, then there is work to be done on how to make support services more acceptable to wider groups of patients. Perhaps most pertinent is the question of whether people ultimately identify with the term cancer patient, or indeed, whether they want to: if the answer is no, then engagement with support services targeted at cancer patients is likely to be low regardless of whether unmet needs are present.

This thesis has highlighted key differences between haematological and solid tumour patients, yet fundamentally the key areas of unmet need are not dissimilar across groups. All patients have psychological needs, physical and practical needs, and the need for information. While there may be some mileage in exploring the unmet needs of other rare cancer groups, the more pertinent question is now how best to meet need in all cancer groups. That there is a relationship between unmet need and psychological wellbeing is becoming evident, but warrants further exploration to determine how it can best be utilised to improve patient outcomes within the clinical setting. If the ultimate aim of any intervention run by healthcare services is to improve patient experience and wellbeing, then implementing interventions that target unmet needs would seem logical. This is the only sure fire way to address causality, therefore making them gold-standard research designs. Not only have unmet needs been shown to relate to psychological wellbeing, but in the wider literature to patient satisfaction (Asadi-Lari, Tamburini & Gray, 2009).

Finally, having made a theoretical contribution to knowledge with the finding that psychological flexibility is influential in the relationship between unmet need and distress, further work is needed to expand upon this finding and to develop psychological interventions to reduce distress in patients. The first step in this process would be to explore how this finding relates to other components within an ACT-based framework. Mindfulness already has a growing evidence base with relation to its success within the cancer setting and there have been studies that have indicated that living a values-based life produces benefits for cancer patients (Ciarrochi et al., 2010). As a tenet of ACT, psychological flexibility has already been shown to produce improvements in wellbeing in cancer patients, it has been utilised as a component of a behavioural change intervention in colorectal cancer patients (Hawkes et al., 2009), but this evidence base is still in its infancy (Hulbert-Williams et al., 2014) and is limited in how widely it has been employed in terms of specific cancer diagnoses. In addition, the success to which such interventions have demonstrated improvements in wellbeing has been variable: existing interventions lack convincing evidence for long term benefits, which may be due to the active components of change not being targeted (Fledderus et al., 2013; Hulbert-Williams et al., 2014). Yet the finding that flexibility moderates the relationship between need and distress highlights ACT as being of prime importance for intervention research.

The findings within this thesis also present an alternative explanation for the mechanism of flexibility in cancer adjustment. It is possible that interventions that aim to raise psychological flexibility in patients who are psychologically inflexible may act to increase awareness and, therefore, distress. This needs to be both explored as a topic of research, but also borne in mind in the ethical design of intervention research with cancer patients. Future research into interventions should seek to expand on earlier work, taking into account the findings from this thesis that indicate that psychological flexibility is the influential in the relationship with distress and therefore a promising candidate for being the active component in the gains seen in ACT interventions. On this assumption, targeting an intervention directly at psychological flexibility will allow for a more streamlined and potentially cost-effective intervention, yet requires considerable thought in how to target an intervention towards the patient group likely to benefit. In the current climate of limited resources, brief interventions have grown in popularity and usage not just within psycho-oncology but across mental health care more generally (Roy-Byrne et al., 2009; McNaughton, 2009). ACT interventions hold particular promise for reducing costs given the evidence that suggest it can be effective both as a brief intervention and that it can be

delivered by non-experts. Producing the largest improvements in the shortest timeframe is ultimately beneficial for all stakeholders: patients, services and commissioners.

Implications for Clinical Practice

There are many implications for clinical practice to be borne out of the research findings contained within this thesis, most of which have been discussed previously. One of the key messages to emerge from this body of work is that unmet needs assessment has a broader clinical utility than has previously been appreciated. The use of needs assessment has increased over recent years due to multiple recommendations (NICE, 2004; APPCG, 2009), yet has typically been used as a way to determine whether additional input is required or to signpost for additional referrals. While such usage is appropriate, this can be expanded upon both in terms of our understanding of why this is helpful for patients, and in understanding potential broader usage of assessments. General maintenance of psychological health is important, even more so in the context of a life-threatening diagnosis. A needs assessment can also be used by the clinical team as a way to monitor psychological health and to ensure that psychosocial care is made available to all. There also needs to be an awareness that if a patient indicates that they have needs in the physical, practical or information domains, that these needs can still impact upon psychological and emotional wellbeing and that the healthcare team need to be engaged in broader discussions with their patients to fully understand the psychosocial impact of cancer. The four patient categories of both need and distress as illustrated in Figure 1 highlight that some patients with high needs fall below distress screening thresholds yet some with high levels of distress do not want help. Thus, for optimal provision of support, both unmet needs and distress measures can be used in combination. Needs assessment provides an excellent initial baseline assessment of the need for additional support, with distress measures having a subsequent utility in being able to guide follow up supportive care.

The findings contained within this thesis shed light on potential ways of reducing distress in cancer patients. The role of psychological flexibility in the relationship between need and distress suggests that psychological interventions with a basis in ACT will be of benefit, yet the connection between unmet need and distress also indicates that more basis clinical interventions may also act to improve psychological health. Findings from the quantitative elements of this thesis indicate that a large number of individual needs items as included

on the SCNS SF34 are related to key psychosocial outcomes: anxiety, depression and quality of life. This suggests that interventions designed to act at lower levels of the stepped care model (NICE, 2004), and that can be provided by all healthcare professionals involved in a patient's care, have the potential to improve these outcomes. Therefore, improved communication, targeted information giving, and improved practical assistance all have the potential to have impact on psychological health in a way that may not have been fully appreciated previously. This thesis adds a new depth to existing work by expanding the application of on-going initiatives and by strengthening the theoretical understanding that must feed into the way in which we seek to support cancer patients in the clinical setting.

Conclusion

Unmet needs are fundamentally linked to distress and to broader psychological health in haematological cancer patients. There are significant relationships between unmet needs, anxiety, depression, quality of life and psychological flexibility. In addition, unmet needs are not confined to the diagnosis and treatment time-points but rather persist into survivorship, a time when support for cancer patients decreases in the UK. It is well recognised that distress is a key issue in cancer patients; this work provides a theoretical contribution to knowledge that may be instrumental in finding new ways to detect and manage distress in the clinical setting. The findings contained within this thesis indicate potentially useful mechanisms to reduce both unmet need and distress in cancer patients: future research needs to build on this work, especially with regards to how patient identity affects the acceptability of support services and the use of ACT –based interventions within the cancer setting. There are, nonetheless, clear implications for clinical practice to emerge from this work: particular areas of unmet need of most relevance to haematological cancer patients have been highlighted and more immediate ways of managing need within the clinical setting have been discussed. Psychosocial need remains common, unmet and distressing in haematological cancer patients. As a system, healthcare services need to work more consistently and coherently to manage psychosocial issues in cancer patients, and ultimately reduce associated levels of distress and improve patient outcomes.

Reference List

Aaronson, N. et al (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute,* 85, 365-376.

Aaronsen, N. (2006). Methodologic issues in assessing the quality of life of cancer patients. *Cancer,* 67(S3), 844-850.

Abrahamson, K., Durham, M. & Fox, R. (2010). Managing the unmet psychosocial and information needs of patients with cancer. *Patient Intelligence,* 2, 45-52.

Ahmedzai, S. et al. (2004). Improving access to specialist palliative care: Developing a screening measure to assess the distress caused by advanced illness that may require referral to specialist palliative care. Sheffield: Sheffield Palliative Care Studies Group: University of Sheffield and Trent Palliative Care Centre.

Anderson, M. & Johnson, J. (1994). Restoration of body image and self-esteem for women after cancer treatment: a rehabilitative strategy. *Cancer Practice,* 2(5), 345-349.

Ansell, P. et al (2007). What determines referral of UK patients with haematological malignancies to palliative care services? An exploratory study using hospital records. *Palliative Medicine, 21*(6), 487-492.

Antoni, M. et al (2001). Cognitive-behavioural stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology,* 20, 20-32.

Applebaum, A. et al (2012). Factors associated with attrition from a randomised control trial of meaning-centered group psychotherapy for patients with advanced cancer. *Psycho-Oncology,* 21(11), 1195-1204.

Ardeshna, K. et al (2003). Long-term effect of a watch and wait policy versus immediate systemic treatment for asymptomatic advanced-stage non-Hodgkin lymphoma: a randomised controlled trial. *The Lancet,* 362, 516-522.

Armes, J. et al (2009). Patients' Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology, 27*(36), 6172-6179.

Asadi-Lari, M., Tamburini, M. & Gray, D. (2004). Patients' needs, satisfaction, and health related quality of life: Towards a comprehensive model. *Health and Quality of Life Outcomes,* 2, 32-47.

Ashbury F., et al (1998). A Canadian survey of cancer patients' experiences: Are their needs being met? *Journal of Pain Symptom Management*, 16:298-306.

Aubeeluck, A. et al (2012). 'All the burden on all the carers': exploring quality of life with family caregivers of Huntington's disease patients. *Quality of Life Research*, 21, 1425–1435

Avis, N. (2000). Sexual function and aging in men and women: community and population-based studies. *The Journal of Gender-specific Medicine,* 3(2), 37-41.

Badr, H. & Carmack Taylor, C. (2009). Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-oncology,* 18, 735-746.

Bailey, D. et al (2004). Uncertainty intervention for watchful waiting in prostate cancer. *Cancer Nursing,* 27(5), 339-346.

Baker-Glenn, E., Park, B., Granger, L., Symonds, P. & Mitchell, A.J. (2011). Desire for psychological support in cancer patients with depression or distress: validation of a simple help question. *Psycho=Oncology,* 20(5), 525-531.

Baxter, A., Scott, K., Vos, T. & Whiteford, H. (2013). Global prevalence of anxiety disorders: a systematic review and meta-regression. *Psychological Medicine,* 43(5), 897-910.

Bell, M. (2012). Bias due to differential attrition: what matters and what may not. Available at: http://sydney.edu.au/medicine/news/news/2012/Oct/GI-abstract-srs1012.pdf. Last accessed on 01/01/2015.

Bland, J. & Altman, D. (1997). Statistics notes: Cronbach's alpha. *British Medical Journal,* 314, 572.

Boberg, E. et al (2003). Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Education and Counselling,* 49, 233-242.

Boehmke, M. & Dickerson, S. (2007). The diagnosis of breast cancer: Transition from health to illness. *Oncology Nursing Forum,* 33, 1121-1127.

Bond, F. et al (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire – II: A revised measure of psychological flexibility and acceptance. *Behavior Therapy,* 42(4), 676-688.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., Boyes, A., & Supportive Care Rev, G. (2000). Evaluation of an instrument to assess the needs of patients with cancer. *Cancer, 88*(1), 217-225.

Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of evaluation in clinical practice, 15*(4), 602-606.

Brain Tumour Research (2013). Report on National Research Funding July 2013. Available at: http://www.braintumourresearch.org/uploads/document/BrainTumourResearchNationalFundingReportJuly_2013draft9_897.pdf. Last accessed on 11/09/2014.

Brennan, J. (2001). Adjustment to cancer – coping or personal transition? *Psycho-oncology,* 10, 1-18.

Brocki J. & Wearden, A. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87 - 108.

Brown, L. et al (2010). The association of depression and anxiety with health-related quality of life in cancer patients with depression and/or pain. *Psycho-Oncology,* 19(7),734-41.

Bryant, J. et al (2014).Examining and addressing evidence-practice gaps in cancer care: a systematic review. *Implementation Science,* 9, 37-44.

Brymer, A. & Cramer, D. (1994). *Quantitative data analysis for social scientists.* Oxford: Routledge.

Bultz, B. & Carlson, L. (2005). Emotional distress: the sixth vital sign in cancer care. *Journal of Clinical Oncology,* 23, 6440-6441.

Buzgova, R., Hajnova, E., Sikorova, L. & Jarosova, D. (2014). Association between unmet needs and quality of life in hospitalised cancer patients no longer receiving anti-cancer treatment. *European Journal of Cancer Care,* 23(5), 685-694.

Cain, E. et al (1983). Psychosocial reactions to the diagnosis of gynecologic cancer. *Obstetrics & Gynecology,* 62(5), 635-641.

Campbell, H.S. et al (2010). Psychometric properties of cancer survivors' unmet needs survey. *Supportive Care in Cancer,* 19**,** 221-230

Cancer Research UK (2013). Non-Hodgkin Lymphoma. Available at: http://publications.cancerresearchuk.org/downloads/Product/CS_REPORT_NHL.pdf. Last accessed on 22/05/2014.

Cancer Research UK (2014). Leukaemia (all subtypes combined) statistics. Available at: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/leukaemia/. Last accessed on 02/07/2014.

Cancer Research UK (2014). Statistics and outlook for acute myeloid leukaemia. Available at: http://www.cancerresearchuk.org/about-cancer/type/aml/treatment/statistics-and-outlook-for-acute-myeloid-leukaemia. Last accessed on 01/01/2015

Caplan, L., Helzlsouer, K., Shapiro, S., Wesley, M. & Edwards, B. (1996). Reasons for delay in breast cancer diagnosis. *Preventative Medicine,* 25(2), 218-224.

Carlson, L.E. & Bultz, B.D. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses. *Psycho-Oncology,* 13(12), 837–849.

Carlson, L. et al (2004) High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer,* 90(12), 2297–2304.

Carlson, L. E., Waller, A., & Mitchell, A. J. (2012). Screening for Distress and Unmet Needs in Patients With Cancer: Review and Recommendations. *Journal of Clinical Oncology, 30*(11), 1160-1177.

Carroll, B., Kathol., R., Noyes, R., Wald, T. Clamon, G. (1993). Screening for depression and anxiety in cancer patients using the Hospital Anxiety and Depression Scale. *General Hospital Psychiatry,* 15(2), 69-74.

Carver, C. et al (1993). How coping mediates the effect of optimism on distress: A study of women with early stage breast cancer. *Journal of Personality and Social Psychology,* 65(2), 375-390.

Carver, C.S. & Antoni, M. H. (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology,* 26, 595-598.

Cella, D.F. et al (1993). The Functional Assessment of Cancer Therapy (FACT) scale: Development and validation of the general measure. *Journal of Clinical Oncology*, 11(3), 570-579.

Cella, D.F. et al (2012). Measuring Health-Related Quality of Life in Leukemia: The Functional Assessment of Cancer Therapy – Leukemia (FACT-Leu) Questionnaire. *Value in Health,* 15(8), 1051-1058.

Chalmers, K. et al (2003). Reports of information and support needs of daughters and sisters of women with breast cancer. *European Journal of Cancer Care,* 12, 81-90.

Ciarrochi, J. Bilich, L., & Godsel, C. (2010). Psychological flexibility as a mechanism of change in Acceptance and Commitment Therapy. In Ruth Baer's (Ed), *Assessing Mindfulness and Acceptance: Illuminating the Processes of Change*.(pp. 51-76). Oakland, CA: New Harbinger Publications.

Ciarrochi, J. & Bailey, A. (2008). A CBT-practitioner's Guide to ACT: How to Bridge the Gap Between Cognitive Behavioral Therapy and Acceptance and Commitment Therapy. Oakland, CA: New Harbinger Publications.

Clarke, J. (2011). What is a systematic review? *Evidence-based nursing, 14*(3), 64-64.

Clavarino, A. M., Lowe, J. B., Carmont, S.-A., & Balanda, K. (2002). The needs of cancer patients and their families from rural and remote areas of Queensland. *The Australian journal of rural health, 10*(4), 188-195.

Clinton-McHarg, T. et al (2014). Anxiety and depression among haematological cancer patients attending treatment centres: Prevalence and predictors. *Journal of Affective Disorders,* 165, 176-181.

Clinton-McHarg, T. et al. (2010). Determining research priorities for young people with haematological cancer: A value-weighting approach. *European Journal of Cancer,* 46, 3263-3270.

Coe, R. (2002). It's the Effect Size, Stupid: What effect size is and why it is important. Paper presented at the British Educational Research Association Conference, Exeter, September. Available at: http://www.leeds.ac.uk/educol/documents/00002182.htm. Last accessed on 02/01/2015.

Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). New Jersey: Lawrence Erlbaum.

Cohen, J. (1994). The earth is round ($p < .05$). *American Psychologist,* 49(12), 997-1003.

Corner, J. et al. (2007). The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *British Journal of Cancer,* 96, 875-881.

Coyle, N. et al (1996). Development and validation of a patient needs assessment tool (PNAT) for oncology clinicians. *Cancer Nursing,* 19, 81-92.

CRUK (2014). Cancer mortality statistics. Available at: http://www.cancerresearchuk.org/cancer-info/cancerstats/mortality/. Last accessed on 01/01/2015.

CRUK (2013). Myeloma. Available et: http://www.cancerresearchuk.org/about-cancer/type/myeloma/. Last accessed on 17/10/2013.

CRUK (2013). Hodgkin Lymphoma. http://www.cancerresearchuk.org/about-cancer/type/hodgkins-lymphoma/. Last accessed on 17/10/2013.

Dahl J., Wilson K.G. & Nilsson A. (2004). Acceptance and Commitment Therapy and the treatment of persons at risk for long-term disability resulting from stress and pain symptoms: a preliminary randomized trial. *Behavior Therapy*, 35, 785–802.

Denford, S., Harcourt, D., Rubin, L. & Pusic, A. (2010). Understanding normality: a qualitative analysis of breast cancer patients concepts of normality after mastectomy and reconstructive surgery. *Psycho-Oncology,* 20(5), 553-558.

Department of Health (2011). Improving outcomes: a strategy for cancer. Available at: https://www.gov.uk/government/publications/the-national-cancer-strategy Last accessed on 02/01/2015.

Department of Health (2012). Quality of life of cancer survivors in England: Report on a pilot survey using Patient Reported Outcome Measures (PROMS). Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213192/9284-TSO-2900701-PROMS.pdf. Last accessed on 01/01/2015.

Detmar, S. B., Aaronson, N. K., Wever, L. D. V., Muller, M., & Schornagel, J. H. (2000). How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *Journal of Clinical Oncology, 18*(18), 3295-3301.

DH, Macmillan Cancer Support & NHS Improvement (2013). Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). Available at: https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes. Last accessed on 12/05/2014.

Doyal, L. & Gough, I. (1991). *A theory of human need.* Palgrave Macmillan , New York, USA.

Earle, E. et al (2005). Follow-up care for childhood cancer survivors: A focus group analysis. *European Journal of Cancer*, 41, 2882–2886

Eccles, S. et al. (2013). Critical research gaps and translational priorities for the successful prevention and treatment of breast cancer. *Breast Cancer Research,* 15, R92.

Edwards, B. & Clarke, V. (2003). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology,* 13(8), 562-576.

Ekman, I. et al (2004). Maintaining Normality and Support Are Central Issues When Receiving Chemotherapy for Ovarian Cancer. *Cancer Nursing,* 27(3), 177-182.

Emmanuel, L., Alpert, H. & Emmanuel E. (2001). Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *Palliative Medicine,* 4(4), 465-74.

Eysenck, H. J. (1995). Meta-analysis of best-evidence synthesis? *Journal of evaluation in clinical practice, 1*(1), 29-36.

Fallowfield, L., Ratcliffe, D., Jenkins, V. & Saul, J. (2001). Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer,* 84(8), 1011-1015.

Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. (2002). Efficacy of a Cancer research UK communications skills training model for oncologists: a randomised controlled trial. *Lancet,* 359, 650–656.

Fenton, K., Johnson, A., McManus, S. & Erens, B. (2001). Measuring sexual behaviour: methodological challenges in survey research. *Sexually Transmitted Infections,* 77, 84-92.

Fielding, R. et al (2013). Attributing variance in supportive care needs during cancer: Culture-service, and individual differences, before clinical factors. *PLOS One,* 8(5), e65099.

First, M. & Gibbon, M. (2004). The Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I) and the Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II). Comprehensive handbook of psychological assessment, Vol. 2: Personality assessment. Hoboken, NJ, US: John Wiley & Sons Inc.

Fledderus, M., Bohlmeijer, E., Fox, JP., Schreurs, K. and Spinhoven, P. (2013). The role of psychological flexibility in a self-help acceptance and commitment therapy intervention for psychological distress in a randomised control trial. *Behaviour Research and Therapy,* 51 (3), 142-151.

Galea, S. & Tracy, M. (2007). Participation Rates in Epidemiologic Studies. *Annals of Epidemiology,* 17(9), 643-653.

Ganz, P. et al (1992). The CARES: a generic measure of health-related quality of life for patients with cancer. *Quality of Life Research,* 1, 19-29.

Gibbs, A. (1997) Focus groups. Available from: http://www.soc.surrey.ac.uk/sru/SRU19.html . Last accessed on 12/11/2013.

Giorgi, A. & Giorgi, B. (2008) Phenomenology. In Jonathan A. Smith (ed). *Qualitative Psychology: A Practical Guide to Research Methods* (2nd ed., pp. 26-52). London: Sage Publications Ltd.

Grande, G., Myers, L. & Sutton, S. (2006). How do patients who participate in cancer support groups differ from those who do not? *Psycho-Oncology,* 15, 321-334.

Green, S. (2005). Systematic reviews and meta-analysis. [Article]. *SMJ Singapore Medical Journal, 46*(6), 270-273.

Grov, E. K., Dahl, A., Moum, T. & Fossa, S. (2005). Anxiety, depression and quality of life in caregivers of patients with cancer in late palliative phase. *Annals of Oncology,* 16, 1185-1191.

Gurevich, M. et al (2002). Stress response syndromes and cancer: conceptual and assessment issues. *Psychosomatics,* 43, 259-281.

Gysels, M., Shipman, C. & Higginson, I. (2008a). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics,* 9, 7-12.

Gysels, M., Shipman, C. & Higginson, I. (2008b). "I Will Do It If It Will Help Others:" Motivations among patients taking part in qualitative studies in palliative care. *Journal of Pain and Symptom Management,* 35, 347-355.

Gysels, M. Evans, C. & Higginson, I. (2012). Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretive synthesis of the literature. *BMC Medical Research Methodology,* 12, 123-140.

Hack, T. F., Degner, L. F., Parker, P. A., & Team, S. C. (2005). The communication goals and needs of cancer patients: A review. *Psycho-Oncology, 14*(10), 831-845.

Halcomb, E. et al (2007). Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups. *Journal of Clinical Nursing,* 16(6), 1000-1011.

Hall, A. et al (2014). The Survivor Unmet Needs Survey (SUNS) for haematological cancer survivors: a cross-sectional study assessing the relevance and psychometric properties. *BMC Health Services Research*, 14, 211.

Hall, A. et al (2013). Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* 22, 2032-2038.

Halldorsdottir, S. and Hamrin, E. (1997). Caring and uncaring encounters within nursing and healthcare from the cancer patient's perspective. *Cancer Nursing,* 20, 120-128.

Halstead, M. & Fernsler, J. (1994). Coping strategies of long-term cancer survivors. *Cancer Nursing*,17(2), 94–100.

Hammond, C. et al (2008). Non-Hodgkin's lymphoma survivors' fertility and sexual function-related information needs. *Fertility and Sterility, 90*(4), 1256-1258.

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer, 17*(8), 1117-1128.

Hawkins, N. et al (2008). Informational needs of patients and perceived adequacy of information available before and after treatment of cancer. *Journal of Psychosocial Oncology, 26*(2), 1-16.

Hayes, A. (2013). *Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach*. New York: Guildford Press.

Hayes, S., Luoma, J., Bond, F., Masuda, A. & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes. *Behaviour Research and Therapy,* 44, 1-25.

Hayes, S.C., Strosahl, K.D. and Wilson K.G. (2011). *Acceptance and Commitment Therapy: The process and practice of mindful change.* New York: Guildford Press.

Helgason, A. R., Dickman, P. W., Adolfsson, J., et al. (2001). Emotional isolation: Prevalence and the effect on well-being among 50-80-year-old prostate cancer patients. Scandinavian Journal of Urology and Nephrology, 35 , 97–101.

Helms, H., O'Hea, E. & Corso, M. (2008). Body image issues in women with breast cancer. *Psychology, Health & Medicine,* 13, 313-325.

Hemingway, H., & Marmot, M. (1999). Clinical evidence - Psychosocial factors in the etiology and prognosis of coronary heart disease: systematic review of prospective cohort studies. *Western Journal of Medicine,* 171(5-6), 342-350.

Higgins, J. P. T., Thompson, S. G., & Spiegelhalter, D. J. (2009). A re-evaluation of random-effects meta-analysis. *Journal of the Royal Statistical Society Series a-Statistics in Society,* 172, 137-159.

HMRN (2014). Incidence. Available at: https://www.hmrn.org/Statistics/incidence. Last accessed on 22/05/2014.

Hodgkinson, K. et al (2007). Assessing unmet supportive care needs in partners of cancer survivors: The development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-Oncology, 16*(9), 805-813.

Hodgkinson, K. et al (2007). The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology, 16*(9), 796-804.

Hodgkinson, K., Butow, P., Hunt, G. E., & Wain, G. (2006). Predictors of psychosocial outcomes and supportive care needs in cured cancer survivors. *Psycho-Oncology, 15*(2), S100-S100.

Holland, J., Watson, M., & Dunn, J. (2011). The IPOS New International Standard of Quality Cancer Care: integrating the psychosocial domain into routine care. *Psycho-Oncology, 20*(7), 677-680.

Holland, J. & Alici, Y. (2010). Management of distress in cancer patients. *The Journal of Supportive Oncology,* 8, 4-12.

Holzner, B. et al (2004). Quality of life of patients with chronic lymphocytic leukemia: results of a longitudinal investigation over 1 yr. *European Journal of Haematology,* 72(6), 381-9.

Hong, J., Tian, J. & Wu, L. (2014). The influence of chemotherapy-induced neurotoxicity on psychological distress and sleep disturbance in cancer patients. *Current Oncology,* 21(4), 174-180.

Hopwood, P. (1993). The assessment of body image in cancer patients. *European Journal of Cancer,* 29, 276-281.

Hordern, A. & Street, A. (2007). Communicating about patient sexuality and intimacy after cancer: mismatched exctations and unmet needs. *Medical Journal of Australia* 186(5): 224-227.

Howell, D. et al (2010). Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. *Palliative Medicine,* 25, 630-641.

Howell, D. A., Shellens, R., Roman, E., Garry, A. C., Patmore, R., & Howard, M. R. (2011). Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. *Palliative Medicine, 25*(6), 630-641.

Howell, D. et al (2013). Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma. *BMJ Supportive and Palliative Care,* 0, 1-7.

Howie J. et al (1999). Quality at general practice consultations: cross sectional survey. *British Medical Journal,* 319, 738-743.

Hubbard, G., Venning, C., Walker, A., Scanlon, K. & Kyle, R. (2014). Supportive care needs of women with breast cancer in rural Scotland. *Supportive Care in Cancer* [Epub ahead of print] Available at: http://www.ncbi.nlm.nih.gov/pubmed/25391226 . Last accessed on 01/01/2015.

Hughes, P.M., Bath, P.A., Ahmed, N. & Noble, B. (2010). What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices. *Palliative Medicine,* 24(1), 68-78.

Hulbert-Williams, N., Storey, L. & Wilson, K. (2014). Psychological interventions for patients with cancer: psychological flexibility and the potential utility of Acceptance and Commitment Therapy. *European Journal of Cancer Care*, 24, 15-27.

Hulbert-Williams, N., Morrison, V., Wilkinson, C. & Neal, R. (2013). Investigating the cognitive precursors of emotional response to cancer stress: Re-testing Lazarus's transactional model. *British Journal of Health Psychology,* 18, 97-121.

Hulbert-Williams, N. et al (2012). The Mini-MAC Scale: Re-analysis of its psychometric properties in a sample of 160 mixed cancer patients. *Psycho-Oncology,* 21, 792-797.

Hunter, J. E., & Schmidt, F. L. (2000). Fixed effects vs. random effects meta-analysis models: Implications for cumulative research knowledge. *International Journal of Selection and Assessment, 8*(4), 275-292.

Ibbotson, T., Maguire, P., Selby, P., Priestman, T. & Wallace, L. (1994). Screening for anxiety and depression in cancer patients: the effects of disease and treatment. *European Journal of Cancer,* 30, 37-40.

Jacobsen, P. et al (1998). Posttraumatic Stress Disorder Symptoms after Bone Marrow Transplantation for Breast Cancer. *Psychosomatic Medicine*, 60(3), 366-371.

Jacobsen, P.B. (2007). Screening for psychological distress in cancer patients: Challenges and opportunities. *Journal of Clinical Oncology,* 25(29), 4526-4527.

Jacobsen, P. & Jim, H. (2008). Psychosocial interventions for anxiety and depression in adult cancer patients: Achievements and challenges. *CA: A Cancer Journal for Clinicians,* 58 (4), 214-230.

Johnson Wright, L., Afari, N. & Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports,* 13(2), 133-138.

Janz, N. et al (2008). Racial/ethnic differences in adequacy of information and support for women with breast cancer. *Cancer,* 113, 1058-1067.

Jenkins, V., Fallowfield, L., & Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centres. *British Journal of Cancer,* 84(1), 48-51.

Johnson, R. & Onwuegbuzie, A. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher,* 33(7), 14-26.

Johnson Vickberg, S. et al (2001). Global meaning and psychological adjustment among survivors of bone marrow transplant. *Psycho-Oncology* 10, 29-39.

Kabat-Zinn, J. (2003). Mindfulness-based interventions in context: Past, present, and future. *Clinical Psychology: Science and Practice* 10(2): 144–156.

Khan, K. S., Kunz, R., Kleijnen, J., & Antes, G. (2003). Five steps to conducting a systematic review. *Journal of the Royal Society of Medicine,* 96(3), 118-121.

Kim, H., Yeom, H., Seo, Y., Kim, N. & Yoo, Y. (2002). Stress and coping strategies of patients with cancer. A Korean study. *Cancer Nursing,* 25(6),425-31.

Koffman, J. et al. (2012). Bereaved relatives' views about participating in cancer research. *Palliative Medicine,* 4(26), 379-383.

Kraus, P. (1999). Body image, decision making, and breast cancer treatment. *Cancer Nursing,* 22(6), 421-427.

Krizek, C., Roberts, C., Ragan, R., Ferrara, J. & Lord, B. (1999). Gender and cancer support group participation. *Cancer Practice,* 7(2), 1065-1074.

Lam, W. et al (2011). Unmet supportive care needs: a cross-cultural comparison between Hong Kong Chinese and German Caucasian women with breast cancer. *Breast Cancer Research and Treatment,* 130, 531-541.

Laubmeier, K., Zakowski, S. & Bair, J. (2004). The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International Journal of Behavioural Medicine,* 11(1), 48:55.

Lazarus, R. (1992). Coping with the stress of illness. *WHO Regional Publications. European Series*, 44, 11-31.

Lazarus, R.S. & Cohen, J.B. (1977). "Environmental Stress". In I. Altman and J.F. Wohlwill (eds.), *Human Behavior and Environment.* (Vol 2) New York: Plenum.

Lepore, S.J. & Coyne, J.C. (2006). Psychological interventions for distress in cancer patients: a review of reviews. *Annals of Behavioral Medicine,* 32**,** 85-92.

Leukaemia & Lymphoma Research (2011). Watch and wait. Monitoring while treatment is not necessary. Available at: https://leukaemialymphomaresearch.org.uk/sites/default/files/watch_and_wait_dec_2011_0.pdf. Last accessed on 12/12/14.

Levin, T.T., Li, Y., Riskind, J. & Rai, K. (2007). Depression, anxiety and quality of life in a chronic lymphocytic leukemia cohort. *General Hospital Psychiatry*, 29, 251–256.

Liang, L. et al (1990). Identifying priorities of psychosocial need in cancer patients. *British Journal of Cancer*, 62, 1000-1003.

Linden, W., Vodermaier, A., Mackenzie, R. & Greig, D. (2012). Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender and age. *Journal of Affective Disorders,* 141, 343-351.

Llewellyn, C. et al (2008). Can we predict which head and neck cancer survivors develop fears of recurrence? *Journal of Psychosomatic Research,* 65, 525–532.

Lobb, E. A. et al (2009). When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Education and Counseling, 77*(1), 103-108.

Lowry, L. & Ardeshna, K. (2012). Has single-agent Rituximab replaced watch-and-wait for a patient with asymptomatic low-grade Follicular Lymphoma? *Cancer Journal,* 18, 390-395.

Mackenzie, N. & Knipe, S. (2006). Research dilemmas: Paradigms, methods and methodology. *Issues in Educational Research,* 16, 193-205.

MacKinnon, D. & Leucken, L. (2008). How and for whom? Mediation and moderation in health psychology. *Health Psychology,* 27(2), S99.

Macmillan (2013). Fighting the fight alone: Isolation among cancer patients. Available at: http://www.macmillan.org.uk/Documents/AboutUs/MAC13970_Isolated_cancer_patients_media_reportFINAL.pdf. Last accessed on 01/01/2015.

Macmillan (2011) Non-Hodgkin Lymphoma. Available at: http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Lymphomanon-Hodgkin/Non-Hodgkinlymphoma.aspx. Last accessed on 21/9/12.

Maher J. & McConnell, H. (2011). New pathways of care for cancer survivors: adding the numbers. *British Journal of Cancer*, 105, S5–S10.

Manitta, V. J., Philip, J. A. M., & Cole-Sinclair, M. F. (2010). Palliative Care and the Hemato-Oncological Patient: Can We Live Together? A Review of the Literature. *Journal of Palliative Medicine, 13*(8), 1021-1025.

Manning, M. & Bettencourt, B. (2011). Depression and medication adherence among breast cancer survivors: bridging the gap with the theory of planned behaviour. *Psychology & Health,* 26(9),1173-87.

Masuda, A & Tully, E. (2012). The role of mindfulness and psychological flexibility in somatization, depression, anxiety, and general psychological distress in a nonclinical college sample. *Journal of Evidence-Based Complementary and Alternative Medicine,* 17(1), 66-71.

McCabe, T. (2014, May 27). My Story: Watching, Waiting and Worrying. Retrieved from: http://lightthenightma.wordpress.com/tag/small-lymphocytic-lymphoma/

McCallum, M. et al (2014). Supportive care needs after gynacologic cancer: Where does sexual health fit in? *Oncology Nursing Forum,* 41, 297-306.

McDowell, M. et al (2010). Prospective predictors of psychosocial support service use after cancer. *Psycho-Oncology,* 20, 788-791.

McGrath, P. (2001). Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nursing,* 24(5), 413-421.

McGrath, P. (2002). Qualitative Findings on the Experience of End-of-Life Care for Haematological Malignancies. *American Journal of Hospice and Palliative Care,* 19(2), 103-111.

McGrath, P., & Joske, D. (2002). Palliative care and haematological malignancy: a case study. *Australian health review : a publication of the Australian Hospital Association, 25*(3), 60-66.

McGrath, P. & Holewa, H. (2006). Special considerations for haematology patients in relation to end-of-life care: Australian findings. *European Journal of Cancer Care*, 16(2), 164-171.

McIllmurray, M. B. et al (2001). The psychosocial needs of cancer patients: findings from an observational study. *European Journal of Cancer Care, 10*(4), 261-269.

McNaughton, J. (2009). Brief interventions for depression in primary care: A systematic review. *Canadian Family Physician,* 55(8), 789-96.

Merckaert, I., Libert Y., & Razavi, D. (2005). Communication skills training in cancer care: where are we and where are we going? *Current Opinion in Oncology,* 17, 319–330.

Meredith, C. et al (1996). Information needs of cancer patients in west Scotland: Cross sectional survey of patients' views. *British Medical Journal,* 313(7059), 724-726.

Mesters, N. et al (2001) Measuring information needs among cancer patients. *Patient Education and Counseling*, 43(3), 253-262.

Mishel, M. (1999) Uncertainty in chronic illness. *Annual Review of Nursing Research,* 7, 269–294.

Mistry, A., Wilson, S., Priestman, T., Damery, S., & Haque, M. (2010). How do the information needs of cancer patients differ at different stages of the cancer journey? A cross-sectional survey. *JRSM short reports, 1*(4), 30-30.

Mitchell, A., Kaar, S., Coggan, C. & Herdman, J. (2008). Acceptability of common screening methods used to detect distress and related mood disorders—preferences of cancer specialists and non-specialists. *Psycho-Oncology,* 17, 226-236.

Mitchell, A. (2011). Detecting and managing psychological distress in women with cancer: an update of recent evidence. *The Obstetrician & Gynaecologist,* 13(1), 22-28.

Mitchell, A. et al (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative care settings: a meta-analysis of 94 interview-based studies. *The Lancet Oncology,* 12, 160-174.

Mitchell, A. (2013). Screening for cancer-related distress: when is implementation successful and when is it unsuccessful? *Acta Oncologica,* 52, 216-224.

Moja, L. P. et al (2005). Assessment of methodological quality of primary studies by systematic reviews: results of the metaquality study cross sectional study. [Article]. *British Medical Journal, 330*(7499), 1053-1055.

Molassiotis, A. et al (2011) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psycho-Oncology,* 20, 88-97

Montori, V. M., Wilczynski, N. L., Morgan, D., Haynes, R. B., & Hedges, T. (2005). Optimal search strategies for retrieving systematic reviews from Medline: analytical survey. *British Medical Journal, 330*(7482), 68-71.

Moorey, S. (2013). 'I know they are distressed. What do I do now?' *Psycho-Oncology,* 22, 1946–1952.

Morrison, V. et al (2012). Common, important, and unmet needs of cancer outpatients. *European Journal of Oncology Nursing, 16*(2), 115-123.

Nagia, A. et al (1993). A comparison of American and Egyptian cancer patient's attitudes and unmet needs. *Cancer Nursing,* 16, PDF only.

National Cancer Action Team (2013). Holistic Needs Assessment for people with cancer. A practical guide for healthcare professionals. Available at: http://www.ncsi.org.uk/wp-content/uploads/Holistic-Needs-Assessment-practical-guide.pdf. Last accessed on 19/05/2014.

National Cancer Institute (2014). Cancer research funding. Available at: http://www.cancer.gov/cancertopics/factsheet/NCI/research-funding. Last accessed on 01/01/2015.

National Cancer Equality Initiative (2010). Reducing cancer inequality: evidence, progress and making it happen - a report by the National Cancer Equality Initiative. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_114354.pdf. Last accessed 01/01/2015.

NCRI (2012). The National Cancer Research Institute (NCRI) and Cancer52 Research into less common cancers: An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012. Available at: http://www.ncri.org.uk/wp-content/uploads/2013/11/2013-NCRI-Research-less-common-cancers-Cancer-521.pdf. Last accessed on 11/09/2014.

NCRI (2013). The National Cancer Research Institute (NCRI) Cancer research in the UK 2002-2011: An overview of the research funded by NCRI Partners. Available at: http://www.ncri.org.uk/wp-content/uploads/2013/11/2013-NCRI-cancer-research-spend-Uk-2002-2011.pdf. Last accessed on 11/09/2014.

Newell, S.A., Sanson-Fisher, R.W. & Savolainen, N.J. (2002). Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *JNCI,* 94, 558-584.

Newman, I., Ridenour, C., Newman, C. & DeMarco, G.M.P., Jr. (2003). A typology of research purposes and its relationship to mixed methods research. In A. Tashakkori & C. Teddlie, (Eds.) *Handbook of mixed methods in social & behavioural research* (pp. 167-188). Thousand Oaks, CA: Sage.

NICE (2003). Improving outcomes in haematological cancers. Available at: http://www.nice.org.uk/guidance/ta251/documents/leukaemia-chronic-myeloid-first-line-dasatinib-nilotinib-and-standarddose-imatinib-appraisal-consultation-document2 Last accessed on 10/07/2015.

NICE (2004). Improving supportive and palliative care for adults with cancer. Available at: https://www.nice.org.uk/guidance/csgsp. Last accessed on 13/12/14.

Norkin, M., Hsu, J. & Wingard, J. (2012). Quality of Life, Social Challenges, and Psychosocial Support for Long-Term Survivors After Allogeneic Hematopoietic Stem-Cell Transplantation. *Seminars in Hematology,* 49(1), 104-109.

Osse, B. et al (2004). Towards a new clinical tool for needs assessment in the palliative care of cancer patients: the PNPC instrument. *Journal of Pain and Symptom Management,* 28, 329-341.

Office for National Statistics (2013). Measuring National Well-being - Health, 2013. Available at: http://www.ons.gov.uk/ons/dcp171766_310300.pdf. Last accessed on 01/01/2015.

Onwuegbuzie, A. & Leech, N. (2004). Enhancing the interpretation of "Significant" Findings: The role of mixed methods research. *The Qualitative Report,* 9, 770-792.

Oxman, A. D. (1994). Systematic reviews – Checklists for review articles. *British Medical Journal, 309*(6955), 648-651.

Palmer, M., Larkin, M., de Visser, R. & Fadden, G. (2010). Developing an Interpretative Phenomenological Approach to Focus Group Data. *Qualitative Research in Psychology,* 7, 99-121.

Park, B. & Hwang, S. (2012). Unmet needs of breast cancer patients relative to survival duration. *Yonsei Medical Journal,* 53, 118-125.

Park, C., Zlateva, I. & Blank, T. (2009). Self-identity after cancer: "survivor", "victim", "patient" and "person with cancer". *Journal of General Internal Medicine,* 23, S430-5.

Parker, P. et al (2001). Breaking bad news about cancer: Patients' preferences for communication. *Journal of Clinical Oncology,* 19(7), 2049-2056.

Paul, C.L. et al. (2011). Cutting the research pie: a value-weighting approach to explore perceptions about psychosocial research priorities for adults with haematological cancers**.** *European Journal of Cancer Care,* 20, 345-353.

Perz, J., Ussher, J., Butow, P. & Wain, G. (2011). Gender differences in cancer carer psychological distress: an analysis of moderators and mediators. *European Journal of Cancer Care,* 20, 610-619.

Pinquart, M. & Duberstein, P. (2010). Depression and cancer mortality: a meta-analysis. *Psychological Medicine,* 40, 1797-1810.

Pitceathly, C. & Maguire, P. (2003). The psychological impact of cancer on patient's partners and other key relatives: a review. *European Journal of Cancer,* 39, 1517-1524.

Pollock, K., Cox, K., Howard, P., Wilson, E. & Moghaddam, N. (2008). Service user experiences of information delivery after a diagnosis of cancer: a qualitative study. *Supportive Care in Cancer,* 16(8), 963-973.

Pope, C. & Mays, N. (1995). Reaching the parts other methods cannot reach: An introduction to qualitative methods in health and health services research. *British Medical Journal,* 311, 42-45.

Preyde, M., et al (2010). Exploratory Survey of Patients' Needs and Perceptions of Psychosocial Oncology. *Journal of Psychosocial Oncology*, 28(3), 320-333.

Przezdziecki, A. et al (2012). My changed body: breast cancer, body image, distress and self-compassion. *Psycho-Oncology,* 22(8), 1872-1879.

Public Health England (2014). Trends in incidence and outcome for haematological cancers in England: 2001-2010. Available at: http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/haematological_cancers/. Last accessed on 01/01/2015.

Puts, M. T. E., Papoutsis, A., Springall, E., & Tourangeau, A. E. (2012). A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment. *Supportive Care in Cancer*, 20(7), 1377-1394.

Quine, L. & Pahl, J. (2006). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transactional model of coping. *Journal of Community and Applied Social Psychology,* 1(1), 57-70.

Refsgaard, B. & Frederiksen, K. (2013). Illness-related emotional experiences of patients living with incurable lung cancer: A qualitative metasynthesis. *Cancer Nursing,* 36(3), 221-228.

Reisfield, G. & Wilson, G. (2004). Use of metaphor in the discourse on cancer. *Journal of Clinical Oncology,* 22, 4024-4027.

Richardson, A. et al (2007). Patients' needs assessment in cancer care: a review of assessment tools. *Supportive Care in Cancer,* 15(10), 1125-44.

Richardson, A. et al (2011). Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review. *British Journal of Cancer,* 105, S82-S94.

Rogers S., Scott, B., Lowe, D., Ozakinci, G. & Humphris, G. (2010) Fear of recurrence following head and neck cancer in the outpatient clinic. *European Archives of Otorhinolaryngology*, 267, 1943–1949.

Roman, E. & Smith, A. (2011). Epidemiology of lymphomas. *Histopathology,* 58, 4-14.

Romsaas, E.P. et al (1983). A method for assessing the rehabilitation needs of oncology outpatients. *Oncology Nursing Forum,* 10(3), 17-21.

Rosenberg, S. et al (2013). Body image in recently diagnosed young women with early breast cancer. *Psycho-Oncology,* 22, 1849-1855.

Roy-Byrne, P. et al (2009). Brief intervention for anxiety in primary care patients. *Journal of the American Board of Family Medicine,* 22(2), 175-86.

Royle, P., Bain, L., & Waugh, N. (2005). Systematic reviews of epidemiology in diabetes: finding the evidence. *BMC medical research methodology, 5*, 2.

Ruddy, K. et al (2013). Young Women with Breast Cancer: A Focus Group Study of Unmet Needs. *Journal of Adolescent and Young Adult Oncology,* 2(4), 153-160.

Ruiz, F. (2010). A Review of Acceptance and Commitment Therapy (ACT) Empirical Evidence: Correlational, Experimental Psychopathology, Component and Outcome Studies. *International Journal of Psychology and Psychological Therapy*, 10, 125-162.

Rutten, L. J. F., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counselling, 57*(3), 250-261.

Rydahl-Hansen, S. (2005). Hospitalized patients experienced suffering in life with incurable cancer. *Scandinavian Journal of Caring Sciences,* 19(3), 213-22.

Sansom-Daly, U., Peate, M., Wakefield, C., Bryant, R. & Cohn, R. (2012) A systematic review of psychological interventions for adolescents and young adults living with chronic illness. *Health Psychology,* 31**,** 380-393.

Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. *Cancer, 88*(1), 225-236.

Sanson-Fisher, R.W., Bonevski, B., Green, L.W. & D'Este, C. (2007). Limitations of the randomized controlled trial in evaluating population-based health interventions. *American Journal of Preventative Medicine,* 33**,** 155-161.

Sanson-Fisher, R.W. et al. (2010). Quality of life research: is there a difference in output between the major cancer types? *European Journal of Cancer Care,* 19, 714-720.

Sanson-Fisher, R. et al (2012). Advancing the evidence in cancer: psychosocial multicentre trials. *Trials,* 13, 171-179.

Satin, J., Linden, W. & Phillips, M. (2009). Depression as a predictor of disease progression and mortality in cancer patients. *Cancer,* 115, 5349-5361.

Sayers, A. (2008). Tips and tricks in performing a systematic review. *British Journal of General Practice,* 58(547), 136-136.

Schnipper, H. (2001). Life after breast cancer. *Journal of Clinical Oncology,* 19, 3581-3584.

Schofield, P. et al (2003). Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology,* 14(1), 48-56.

Schofield, P. et al. (2008). Lung cancer: challenges and solutions for supportive care intervention research. *Palliative and Supportive Care,* 6, 281-287.

Schofield, P. et al. (2012). Cancer Treatment Survey (CaTS): Development and validation of a new instrument to measure patients' preparation for chemotherapy and radiotherapy. *Psycho-Oncology,* 21(3), 307-315.

Schroder, K., Carey, M. & Vanable, P. (2003). Methodological challenges in research on sexual risk behaviour II: Accuracy of self-reports. *Annals of Behavioural Medicine,* 26(2), 104-123.

Seale, C. (2001). Sporting cancer: struggle language in news reports of people with cancer. *Sociology of Health and Illness,* 23, 308-329.

Siu, M., Catton, P., Jones, J., and Jadad, J.R. (2013). A pilot study examining the unmet needs of cancer survivors living with polypathology. *Current Issues in Oncology,* 20(3), e266-e269.

Shaw, C. (1999). A framework for the study of coping, illness behaviour and outcomes. *Journal of Advanced Nursing,* 29(5), 1246-1255.

Shea, B. et al (2007). Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. *BMC medical research methodology, 7*.

Sheard, T & Maguire, P. (1999). The effect of psychological intervention on anxiety and depression in cancer patients: results of two meta-analyses. *British Journal of Cancer,* 80(11), 1770-1780.

Sherman, R. et al (2005). Dialogue among survivors of hematopoietic cell transplantation: Support group themes. *Journal of Psychosocial Oncology,* 23(1), 1-24.

Smith, J.A., Flowers, P. & Larkin, M. (2009) *Interpretative phenomenological analysis: theory, method and research*. Los Angeles: Sage.

Smith, J.& Osborn, M. (2008) Interpretative phenomenological analysis. In JA Smith (Ed) Qualitative Psychology: A Practical Guide to Methods (second ed) London: Sage.

Smith, J. A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54.

Smith, M., Redd, W., Peyser, C. & Vogl, D. (1999). Post-traumatic stress disorder in cancer: A review. *Psycho-oncology,* 8(6), 521-537.

Smith, V., Devane, D., Begley, C. M., & Clarke, M. (2011). Methodology in conducting a systematic review of systematic reviews of healthcare interventions. *BMC medical research methodology, 11*, 15-21.

So, W. et al (2010). Anxiety, depression and quality of life among Chinese breast cancer patients during adjuvant therapy**.** *European Journal of Oncology Nursing,* 14(1), 17-22.

Sollner, W. et al. (2001) How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer*, 84(2), 179-185.

Sontag S. (1978) *Illness as Metaphor*. Vintage Press, New York, USA.

Soothill, K. et al (2004). Grouping cancer patients by psychosocial needs*. Journal of Psychosocial Oncology*, **22**(2), 89-109.

Soothill, K., et al (2003). The universal, situational, and personal needs of cancer patients and their main carers. *European journal of oncology nursing*, 7(1), 5-13.

Soothill, K. et al (2001). The significant unmet needs of cancer patients: probing psychosocial concerns. *Supportive Care in Cancer,* 9(8), 597-605.

Spiegel, D. & Giese-Davis, J. (2003). Depression and cancer: mechanisms and disease progression. *Mood Disorders and Medical Illness,* 54, 269-282.

Stanton, A.L., Leucken, L.J., MacKinnon, D.P. and Thompson, E.H. (2012). Mechanisms in psychosocial interventions for adults living with cancer: Opportunity for integration of

theory, research, and practice. *Journal of Consulting and Clinical Psychology, 81(2)*, 318-335.

Stanton, A. (2006). Psychosocial concerns and interventions for cancer survivors. *Journal of Clinical Oncology,* 24, 5132-5137.

Stanton, A., Danoff-Burg, S. & Huggins, M. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psycho-oncology,* 11, 93-102.

Stark, D. et al (2002). Anxiety disorders in cancer patients: Their nature, associations, and relation to quality of life. *Journal of Clinical Oncology,* 20(14), 3137-3148.

Stark, D. & House, A. (2000). Anxiety in cancer patients. *British Journal of Cancer,* 83(10), 1261-1271.

Stewart, R., Caird, J., Oliver, K. & Oliver, S. (2011). Patients' and clinicians' research priorities. *Health Expectations,* 14, 439-448.

Stirling, A., Wilson, P. & McConnachie (2001). Deprivation, psychological distress, and consultation length in general practice. *British Journal of General Practice,* 51, 456-460.

Surbone, A. et al (2010). Psychosocial care for patients and their families is integral to supportive care in cancer: MASCC position statement. *Supportive Care in Cancer,* 18, 255-263.

Swift, P. et al (2014). Living with anxiety: Understanding the role and impact of anxiety in our lives. Available at: http://www.mentalhealth.org.uk/content/assets/PDF/publications/living-with-anxiety-report.pdf?view=Standard Last accessed on 01/01/2015.

Tamburini, M. et al (2000). Assessment of hospitalized cancer patients' needs by the needs evaluation questionnaire. *Annals of Oncology,* 11, 31–37.

Takahashi, M. et al (2007). Impact of breast cancer diagnosis and treatment on women's sexuality: a survey of Japanese patients. *Psycho-oncology,* 17(9), 901-907.

Taylor, S. et al (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology,* 54(5), 608-615.

Taylor S.E. (1983) Adjustment to threatening events: a theory of cognitive adaptation. *American Psychologist*, 58, 1161–1173.

Taylor-Ford, M. et al (2013). Body image predicts quality of life in men with prostate cancer. *Psycho-Oncology,* 22, 756-761.

Thomas, C. et al (2001). What are the psychosocial needs of cancer patients and their carers? Available at: http://eprints.lancs.ac.uk/13787/1/Psychosocial_Needs_Report.pdf . Last accessed on 02/01/2015.

Turner, J., Kelly, B., Swanson, C., Allison, R. & Wetzig, N. (2005). Psychosocial impact of newly diagnosed advanced breast cancer. *Psycho-Oncology,* 14(5), 396-407.

Uchida, M. et al (2011). Patients' supportive care needs and psychological distress in advanced breast cancer patients in Japan. *Japanese Journal of Clinical Oncology,* 41(4), 530-536.

Ussher, J., Kirsten, L., Butow, P. & Sandoval, M. (2006). What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine,* 62(10), 2565-2576.

Von Heymann-Horan, A. et al (2013). Unmet needs of women with breast cancer during and after primary treatment: A prospective study in Denmark. *Acta Oncologica,* 52, 382-390.

Watson, E. et al (2012). Personalised cancer follow-up: risk stratification, needs assessment or both? *British Journal of Cancer,* 106(1), 1-5.

Watson, M. & Bultz, B. (2010). Distress, the 6th vital sign in cancer care. *Psycho-Oncologie,* 4, 159-163.

Watson, M. et al (1988). Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychological Medicine,* 18, 203-209.

Weber, C. et al (2001). Body experience and mental representation of body image in patients with haematological malignancies and cancer as assessed with the Body Grid. *British Journal of Medical Psychology,* 74(4):507-21.

Wen, K.-Y., & Gustafson, D. H. (2004). Needs assessment for cancer patients and their families. *Health and quality of life outcomes,* 2, 11.

Wicksell, R., Melinn, L., Lekander, M. & Olsson, G. (2009). Evaluating the effectiveness of exposure and acceptance strategies to improve functioning and quality of life in longstanding pediatric pain – A randomized controlled trial. *Pain,* 141, 248-257.

Wilczynski, N. L., Haynes, R. B., & Hedges, T. (2007). EMBASE search strategies achieved for retrieving methodologically high sensitivity and specificity sound systematic reviews. *Journal of Clinical Epidemiology,* 60(1), 29-33.

Wright, B. & Forbes, K. (2014). Haematologists' perceptions of palliative care and specialist palliative care referral: a qualitative study. *BMJ Supportive & Palliative Care,* Online First: 24 September 2014 doi:10.1136/bmjspcare-2014-000689.

Wright, P. et al (2008). Measurement and interpretation of social distress using the social difficulties inventory (SDI). *European Journal of Cancer,* 44, 1529-1535.

Young, N. et al (2012). Holistic Needs Assessment and Care Planning. Available at: http://www.ncsi.org.uk/wp-content/uploads/HNA-and-CP-Sharing-Good-Practice.pdf. Last accessed on 02/01/2015.

Zabora, J. et al (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology,* 10(1), 19–28.

Zigmond, A.S. & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica,* 67, 361-370.

Zittoun, R. et al (1999). Assessment of quality of life during intensive chemotherapy or bone marrow transplantation. *Psycho-Oncology, 8*(1), 64-73.

Appendices

Appendix 1: Example data extraction form

Data Extraction Form - 1

Author: Andrykowski, MA, Cordova, MJ, Hann, DM, Jacobsen, PB, Fields, KK, Phillips, G.

Year: 1999

Country: USA

Reference: Andrykowski, M.A. et al, (1999) Patients' psychosocial concerns following stem cell transplantation. *Bone Marrow Transplantation* 24: 1121-1129.

Source: Bone Marrow Transplantation (journal)

Study objective: To determine the nature, frequency, correlates and temporal trajectory of concerns of stem cell transplant recipients.

Sample description: SCT recipients. Mean age of 46, mean 17 months post SCT. Mixed cancer sample. 61% female.

Recruitment: Drawn from the roster of SCT recipients at either the Blood and Marrow Transplant Programme at the University of Kentucky or the Blood and Marrow Transplant Programme at the Moffitt Cancer Centre.

Sample size: 110

Inclusion and exclusion criteria: At least 18 years of age; have undergone either autologous or allogenic SCT for malignant disease; have no current evidence of malignant disease; be living outside of the hospital; have undergone SCT between 2 months and 6 years prior; read, write and understand English; provide written informed consent.

Time period:

Setting: Patients were recruited at hospital and then completed the questionnaire at home.

Intervention (if applicable): N/A questionnaire study

Outcome measures used: Questionnaire – demographic information, SCT Concerns Questionnaire, WHO performance scale.

Statistics: SPSS – multiple regression analysis, one way ANOVA, chi-square

Limitations: Not using a longitudinal design. Lack of a comparison group. Sample recruited from only 2 centres – diversity. Females and breast cancer patients overrepresented in sample. Severity of concerns not assessed, merely presence.

Implications: Identified common concerns in people post-SCT, has the potential to guide future interventions. Identified clinical and demographic information that is linked to the likelihood that specific concerns will be reported.

Author comments: Talks about use for future interventions

Reviewer comments:

Appendix 2: Example quality assessment form

1. Question / objective sufficiently described? YES
2. Study design evident and appropriate? YES
3. Method of subject/comparison group selection or source of information/input variables described and appropriate? YES
4. Subject (and comparison group, if applicable) characteristics sufficiently described? YES
5. If interventional and random allocation was possible, was it described? N/A
6. If interventional and blinding of investigators was possible, was it reported? N/A
7. If interventional and blinding of subjects was possible, was it reported? N/A
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? means of assessment reported? YES
9. Sample size appropriate? YES
10. Analytic methods described/justified and appropriate? YES
11. Some estimate of variance is reported for the main results? YES
12. Controlled for confounding? YES
13. Results reported in sufficient detail? YES
14. Conclusions supported by the results? YES

Score: 22/22

Appendix 3: Stage one of thematic analysis of existing needs assessment tools.

Table to summise the first stage of the thematic analysis of existing needs assessment tools. Table includes the name of the tool, each item included in the assessment and the area of need that each question corresponds with.

Assessment Tool	**Item**	**Theme**
PNAT (Patient Needs Assessment Tool)	Mobility	Mobility
	Communication	Communication
	ADL's	Physical Functioning
	Bowel and Bladder Function	Physical Functioning
	Discomfort	Pain / Discomfort
	Alertness and mentation	Cognitive Function
	Prior psychological adjustment	Coping
	Depression	Depression
	Anxiety	Anxiety
	Attitude towards disease	Coping
	Attitude towards treatment	Pessimism
	Practical support	Practical issues
	Individual support network	Support networks
	Non-medical support network	Support networks
	Medical support network	Availability of medical care
	Financial security	Financial
NEST	1	Financial
	2	Availability of medical care
	3	Support networks
	4	Practical issues

	5	Psychological wellbeing
	6	Spiritual
	7	Relationships
	8	Benefit finding
	9	Physical functioning
	10	Depression / anxiety
	11	Relationship with medical team
	12	Communication
	13	Communication
PNPC (Problems and Needs in Palliative Care Questionnaire)	ADL's and Instrumental Activities of Daily Living	
	1	Practical issues
	2	Practical issues
	3	Practical issues
	4	Practical issues
	5	Practical issues
	6	Practical issues
	7	Practical issues
	Physical symptoms	
	1	Pain / discomfort
	2	Cognitive functioning
	3	Fatigue
	4	Sleeping problems
	5	Physical functioning
	6	Physical functioning
	7	Physical functioning
	8	Physical functioning
	9	Physical functioning
	10	Physical functioning
	11	Physical functioning
	12	Physical functioning

	13	Appearance
	14	Physical functioning
	15	Sexual needs
	16	Physical functioning
	17	Physical functioning
	18	Physical functioning
	Role Activities	
	1	Identity
	2	Psychological wellbeing
	3	Employment
	4	Practical issues
	Financial and administrative issues	
	1	Financial
	2	Financial
	3	Practical issues
	4	Practical issues
	5	Practical issues
	Social issues	
	1	Relationships
	2	Support networks
	3	Relationships
	4	Relationships
	5	Guilt
	6	Perceptions of others
	7	Disagreements
	8	Support networks
	9	Someone to talk to
	10	Practical issues
	11	Perceptions of others
	12	Perceptions of others
	13	Perceptions of others
	14	Loneliness

	15	Loneliness
	Psychological issues	
	1	Depression
	2	Depression
	3	Fear
	4	Fear
	5	Fear
	6	Fear
	7	Fear
	8	Coping
	9	Communication
	10	Guilt
	11	Shame
	12	Emotional wellbeing
	13	Appearance
	14	Benefit finding
	15	Coping
	Spiritual issues	
	1	Identity
	2	Relationships
	3	Spiritual
	4	Spiritual
	5	Acceptance
	Autonomy	
	1	Autonomy
	2	Social
	3	Autonomy
	4	Autonomy
	5	Autonomy
	6	Autonomy
	7	Autonomy
	8	Autonomy
	9	Autonomy

	Information Needs	
	1	Information
	2	Information
	3	Information
	4	Information
	5	Information
	6	Information
	7	Information
	8	Information
	9	Information
	Problems in consultations	
	1	Communication
	2	Communication
	3	Communication
	Overriding problems in quality of care	
	1	Medical care
	2	Medical care
	3	Medical care
	4	Medical care
	5	Medical care
	6	Medical care
	7	Medical care
	8	Medical care
	9	Medical care
	Concerning the GP	
	1	Medical care
	2	Medical care
	3	Medical care
	4	Medical care
	5	Medical care
	6	Medical care
	7	Medical care

	8	Medical care
	9	Medical care
	10	Medical care
	11	Medical care
	12	Medical care
	13	Medical care
	14	Medical care
	15	Medical care
	16	Medical care
	17	Medical care
	18	Medical care
	19	Medical care
	20	Medical care
	Concerning the specialist	
	1	Information
	2	Medical care
	3	Medical care
	4	Medical care
	5	Medical care
	6	Medical care
	7	Medical care
	8	Medical care
	9	Medical care
	10	Medical care
	11	Medical care
	12	Medical care
	13	Medical care
	14	Medical care
	15	Medical care
	16	Medical care
	17	Medical care
	18	Medical care
	19	Medical care

NEQ (Needs Evaluation Questionnaire)	1	Information
	2	Information
	3	Information
	4	Information
	5	Involvement in care
	6	Information
	7	Relationship with medical team
	8	Communication
	9	Pain / discomfort
	10	Practical issues
	11	Respect as an individual
	12	Medical care
	13	Medical care
	14	Medical care
	15	Financial
	16	Financial
	17	Psychological wellbeing
	18	Spiritual
	19	Peer support
	20	Support networks
	21	Identity
	22	Support networks
	23	Perceptions of others
SCNS-LF59	1	Pain / discomfort
	2	Fatigue
	3	Physical functioning
	4	Physical functioning
	5	Sleeping problems
	6	Practical issues
	7	Independence

	8	Independence
	9	Spiritual
	10	Psychological wellbeing
	11	Anxiety
	12	Depression
	13	Depression
	14	Disease fears
	15	Disease fears
	16	Disease fears
	17	Treatment worries
	18	Disease fears
	19	Acceptance
	20	Treatment worries
	21	Uncertainty
	22	Control of own illness
	23	Making the most of life
	24	Keeping positive
	25	Spiritual
	26	Spiritual
	27	Changes to lifestyle
	28	Peer support
	29	Perceptions of others
	30	Sexual needs
	31	Sexual needs
	32	Concerns about others
	33	Concerns about others
	34	Financial
	35	Practical issues
	36	Medical care
	37	Support networks
	38	Respect as an individual
	39	Involvement in care
	40	Involvement in care

	41	Respect as an individual
	42	Medical care
	43	Respect as an individual
	44	Relationship with medical team
	45	Peer support
	46	Information
	47	Information
	48	Information
	49	Information
	50	Communication
	51	Communication
	52	Information
	53	Information
	54	Psychological support
	55	Information
	56	Respect as an individual
	57	Environment
	58	Involvement in care
	59	Having a key worker
NAT	1	Spiritual
	2	Financial
	3	Practical issues
	4	Social factors
	5	Psychological wellbeing
	6	Physical functioning
	7	Information
	8	Caregiver wellbeing
	9	Caregiver wellbeing
	10	Caregiver wellbeing
	11	Caregiver wellbeing
	12	Caregiver wellbeing

	13	Caregiver wellbeing
	14	Caregiver wellbeing
	15	Caregiver wellbeing
CARES (Cancer Rehabilitation Evaluation System)	1	Physical functioning
	2	Physical functioning
	3	Physical functioning
	4	Physical functioning
	5	Practical issues
	6	Practical issues
	7	Practical issues
	8	Practical issues
	9	Social roles
	10	Social roles
	11	Social roles
	12	Activities
	13	Physical functioning
	14	Physical functioning
	15	Eating
	16	Eating
	17	Eating
	18	Employment
	19	Employment
	20	Pain / discomfort
	21	Pain / discomfort
	22	Pain / discomfort
	23	Pain / discomfort
	24	Appearance
	25	Appearance
	26	Appearance
	27	Information
	28	Involved in care

	29	Involved in care
	30	Communication
	31	Communication
	32	Communication
	33	Communication
	34	Communication
	35	Communication
	36	Involved in care
	37	Involved in care
	38	Appearance
	39	Appearance
	40	Body Image
	41	Anxiety
	42	Depression
	43	Anger
	44	Psychological wellbeing
	45	Coping
	46	Sleeping problems
	47	Cognitive functioning
	48	Cognitive functioning
	49	Cognitive functioning
	50	Relationships with friends and family
	51	Relationships with friends and family
	52	Relationships with friends and family
	53	Relationships with friends and family
	54	Relationships with friends and family
	55	Relationships with friends and family

	56	Relationships with friends and family
	57	Relationships with friends and family
	58	Relationships with friends and family
	59	Relationships with friends and family
	60	Support networks
	61	Support networks
	62	Relationships with friends and family
	63	Relationships with friends and family
	64	Anxiety around treatment
	65	Anxiety around treatment
	66	Anxiety around treatment
	67	Anxiety around treatment
	68	Anxiety around treatment
	69	Anxiety around treatment
	70	Anxiety around treatment
	71	Disease fears
	72	Worries about the future
	73	Worries about the future
	74	Sexual needs
	75	Sexual needs
	76	Sexual needs
	77	Sexual needs
	78	Medical care
	79	Medical care
	80	Medical care
	81	Medical care
	82	Financial

	83	Financial
	84	Practical issues
	85	Appearance
	86	Anxiety around treatment
	87	Physical functioning
	88	Physical functioning
	89	Childcare
	90	Concerns about children
	91	Concerns about children
	92	Employment
	93	Employment
	94	Employment
	95	Employment
	96	Employment
	97	Employment
	98	Employment
	99	Sexual needs
	100	Sexual needs
	101	Sexual needs
	102	Sexual needs
	103	Relationship
	104	Relationship
	105	Relationship
	106	Relationship
	107	Relationship
	108	Relationship
	109	Relationship
	110	Relationship
	111	Relationship
	112	Relationship
	113	Relationship
	114	Relationship
	115	Relationship

	116	Relationship
	117	Relationship
	118	Relationship
	119	Relationship
	120	Relationship
	121	Relationship
	122	Relationship
	123	Relationship
	124	Relationship
	125	Relationship
	126	Problems with treatments
	127	Problems with treatments
	128	Problems with treatments
	129	Problems with treatments
	130	Problems with treatments
	131	Problems with treatments
	132	Problems with treatments
	133	Problems with treatments
	134	Problems with treatments
	135	Problems with treatments
	136	Problems with treatments
	137	Problems with

		treatments
	138	Problems with treatments
	139	Problems with treatments
ISNQ (Information and Support Needs Questionnaire)	1	Information
	2	Information
	3	Information
	4	Information
	5	Information
	6	Regular appointments
	7	Information
	8	Information
	9	Information
	10	Information
	11	Information
	12	Communication
	13	Support to be independent
	14	Support to be independent
	15	Knowledgeable professionals
	16	Information
	17	Communication
	18	Information
	19	Support with family issues
	20	Information
	21	Information
	22	Information
	23	Information

	24	Support
	25	Information
	26	Information
	27	Support
	28	Someone to talk to
	29	Peer support
PNI (Patient Needs Inventory)	1	Health professional
	2	Health professional
	3	Health professional
	4	Communication
	5	Respect as an individual
	6	Communication
	7	Communication
	8	Health professional
	9	Involvement in care
	10	Information
	11	Information
	12	Information
	13	Information
	14	Information
	15	Support network
	16	Support network
	17	Support network
	18	Someone to talk to
	19	Support network
	20	Childcare
	21	Spiritual
	22	Emotional wellbeing
	23	Uncertainty
	24	Spiritual
	25	Spiritual
	26	Psychological wellbeing

	27	Concerns about others
	28	Spiritual
	29	Peer support
	30	Loneliness
	31	Religious
	32	Anger
	33	Spiritual
	34	Guilt
	35	Sexual needs
	36	Independence
	37	Maintaining control
	38	Appearance
	39	Perceptions of others
	40	Identity
	41	Psychological support
	42	Practical issues
	43	Fatigue
	44	Eating
	45	Practical issues
	46	Practical issues
	47	Financial
	48	Practical issues
OCPC (Oncology Clinic Patient Checklist)		Information
		Fatigue
		Pain
		Physical - eating related
		Physical - communication
		Breathing
		Physical - toileting related
		Transportation
		ADLs
		Practical assistance at

		home
		Medical supplies
		Employment
		Social activities
		Psychological
		Concerns about family
		Relationships
		Treatment side effects
SPARC	1	Someone to talk to
	2	Pain
	3	Memory
	4	Symptoms
	5	Symptoms
	6	Breathings
	7	Symptoms
	8	Symptoms
	9	Symptoms
	10	Symptoms
	11	Toileting
	12	Toileting
	13	Symptoms
	14	Symptoms
	15	Sleeping
	16	Sleeping
	17	Appetite
	18	Weight
	19	Symptoms
	20	Appearance
	21	Symptoms
	22	Control over symptoms
	23	Anxiety
	24	Low mood

	25	Confusion
	26	Concentration
	27	Loneliness
	28	Depression
	29	Depression
	30	Depression
	31	Sexual
	32	Worries about death
	33	Religious needs
	34	Independence
	35	ADLs
	36	Household tasks
	37	Feeling alone
	38	Concerns about family
	39	Support from family
	40	Amount of help needed
	41	Treatment
	42	Treatment
	43	Personal affairs
	44	Someone to talk to
	45	Information
CaSUN		
	1	Information
	2	Information for others
	3	Understandable information
	4	High quality medical care
	5	Accessible health care
	6	To feel involved
	7	Staff communication
	8	Medical accountability
	9	Access to alternative

		therapies
	10	Stress
	11	Treatment complications
	12	Adjustment
	13	Fertility
	14	Employment
	15	Financial support/benefits
	16	Insurance
	17	Legal services
	18	Parking
	19	Fear of recurrence
	20	Emotional support
	21	Supporting others
	22	Impact on others
	23	New relationships
	24	Peer support
	25	Talking about cancer
	26	Body image
	27	Sexual
	28	Key worker
	29	Moving on
	30	Changes in beliefs
	31	Perceptions of others
	32	Expectations of others
	33	Making decisions despite uncertainty
	34	Spiritual beliefs
	35	Making life count
	36	N/A
	37	N/A
	38	N/A
	39	N/A

	40	N/A
	41	N/A
	42	N/A

Appendix 4: Stage two of thematic analysis of existing needs assessment tools.

All items to emerge from the thematic analysis of existing needs assessment tools.

All Items
Mobility
Communication
Physical functioning
Pain / discomfort
Cognitive function
Coping
Depression
Anxiety
Pessimism
Practical issues
Support networks
Availability of medical care
Financial
Spiritual
Benefit finding
Psychological wellbeing
Relationships
Relationship with medical team
Fatigue
Sleeping problems
Appearance
Sexual needs
Identity
Employment
Someone to talk to
Disagreements
Perceptions of others

Loneliness
Fears
Guilt
Shame
Emotional wellbeing
Acceptance
Autonomy
Social
Information
Medical care
Involvement in care
Respect as an individual
Peer support
Independence
Disease fears
Treatment worries
Uncertainty
Control over own illness
Making the most of life
Keeping positive
Changes to lifestyle
Concerns about others
Psychological support
Environment
Having a key worker
Social factors
Caregiver wellbeing
Social roles
Activities
Eating
Body image
Anger
Relationships with friends and family

Anxiety around treatment
Worries about the future
Childcare
Concerns about children
Relationship
Problems with treatments
Regular appointments
Support to be independent
Support with family issues
Health professional
Maintaining control

Appendix 5: Tabulated items from thematic analysis of needs assessment tools.

Items from thematic analysis of needs assessment tools grouped into needs domains as presented to participants of the focus group.

Physical	***Psychological***	***Identity***	***Social***
Mobility	Coping	Body image	Support networks
Pain	Depression	Independence	Relationship with partner
Discomfort	Anxiety	Respect as an individual	Relationship with family
Fatigue	Feeling upset	Maintaining a sense of control	Relationship with friends
Sleeping problems	Keeping positive		Children
Eating related	Wellbeing		Forming new relationships
Drinking related	Someone to talk to		Perceptions of other
Ability to do the things I used to do	Support from professionals		Expectations of others
Breathing	Peer support		Feeling different
Bathroom related	Loneliness		
Washing and dressing	Negative emotions		
Weight	Adjusting to my diagnosis		
	Stress		
	Fear of recurrence		
	Changes in my beliefs		
	Uncertainty		
	Anger		
	Moving on		

Practical Issues	***Medical/Health Professional***	***Sexual***	***Information***
Childcare	Availability of medical care	Sexual Needs	Receiving understandable information
Transport	Relationship with medical team	Fertility	Information for others
Household tasks	Quality of medical care		
Parking	Worries about illness		
Insurance	Worries about treatment		
Personal affairs	Having a key worker		
	Environment		
	Involvement in care		

Availability of medical supplies
Access to alternative therapies
Treatment side effects

Communication

Bringing up the topic of cancer
Communicating with medical staff

Cognitive Function

Memory
Concentration
Understanding

Financial

Financial support

Spiritual

Acceptance
Worries about the future
Religious beliefs

Employment

Gaining employment
Maintaining employment

Appendix 6: Key areas of need for each participant.

Each participant was asked to highlight the individual needs from the list as presented in Appendix 3 that had been most important to them during their experience.

David	**William**	**James**
Keeping positive	Fatigue	Fatigue
Expectation of recurrence	Weight	Eating related
Support networks	Coping	Receiving understandable information
Expectations of others	Keeping positive	Information for others
Insurance	Parking	Financial support
Having a key worker	Having a key worker	
Receiving understandable information	Treatment side effects	
Bringing up the topic of cancer	Receiving understandable information	
Acceptance	Financial support	
Mark	**Ray**	**Daphne**
Discomfort	Sleeping problems	Pain
Eating related	Fatigue	Fatigue
Washing and dressing	Mobility	Sleeping problems
Weight loss	Eye sight	Eating related
Anxiety	Hearing	Keeping positive
Keeping positive	Parking	Support from professionals
Adjusting to my diagnosis	Having a key worker	Adjusting to my diagnosis
Fear of recurrence	Information needs to be available	Fear of recurrence
Body image (appearance and outward manifestation of disease)	Information about side effects	Body image

Relationship with partner	Peer support	Relationship with partner
Parking	Unable to work	Having a key worker
Availability of medical care	Anxiety and depression after remission	Relationship with medical team
Relationship with medical team	Memory	Access to alternative therapies
Quality of medical care	Concentration	Bringing up the topic of cancer
Worries about illness	Help dealing with DWP	Peer support
Treatment side effects	Being positive	Concentration
Receiving understandable information		

Appendix 7: Quotations from each participant corresponding with areas of need from which the final analysis structure was developed.

		David	**William**	**James**	**Mark**	**Ray**	**Daphne**
Theme	**Sub-themes**						
Care	**Treatment**	I wasn't very happy with the treatment I was getting there P1; “you expect the treatment to make you feel ill. That’s what I found, when I started it, I expected to feel bad” P1	"I was in a week later, for an operation, and, erm, which was quite an interesting experience" P2	"you’re struggling against this nasty little disease and very nasty treatment" P3	"When you’re in it and the treatment is there and you think, right, from here we’re going to have chemo next, we’re going to have this next, we’ll have reconstructive	"Treatment side-effects, I think it's absolutely vital on that list." P5;	“the side effects of the treatment. You need more help.” P6; "is that what we're supposed to expect after?" P6

					stuff" P4		
	Diagnosis	"basically I sat in front of him and he said 'you've got cancer'" P1; "he said, what you got is probably incurable, and you need to see a specialist. And then, off you go. So." P1	"I think he knew what was the matter, but he didn't say anything to me, he fast-tracked me to the hospital" P2	"when they do tell you it's cancer… it knocks the wind out of your sails" P3	that's the most stressful part of it all I reckon P4	the diagnosis process was rather fraught P5	"it was a hell of a relief to know there was something wrong, rather than me thinking it was…" P6
Psychological	**Psychological**	"it's always in the back of your mind, it never leaves you" P1	.	"I think the anxiety there is, um, probably you get a bit anxious about knowing everything that's going	"they're the ones which I felt most strongly and they're the ones which I didn't get any help with" P4	And I was in one hell of a state. Mentally. And, I still am. P5	"I think you cover a lot up" P6

				on, erm, and is it going to… is it going to work" P3			
	Emotional	"on my first birthday, I was driving down, and tears were streaming down" P1	"Being positive, and not let it get you down at all. Trust, and be positive" P2	.	"I think the emotional bit comes right at the end" P4	"one very tearful evening where I thought this could possibly be my last Christmas" P5;	"I was so angry, and I mean angry." P6
	Guilt					"I think there's a certain amount of guilt there yes" P5	.
	Coping	instead of feeling sorry for myself I'd write about the previous day P1	I do some charity work with the cancer and lymphoma local group P2	.	But... I couldn't get into that big emotional feeling P4	I'm not a religious person but, erm, putting words... together... I	.

						found helped, helped me cope P5	
	FoR	you have to get into a position mentally where you accept the recurrence, rather than fear it P1	.	"And I suppose you do things like, if you notice a little mole on the back of your hand, it can be a problem" P3	.	you get the little aches and pains. They usually start as I was saying about a fortnight before my next check up P5	"worries for the future, I can't say that's not a… you don't want, you never want to face the facts do you" P6
	End of treatment				"you kind of get fired off at the end" P4	"My problems arose after I'd finished the chemo. And, I just finished. I had nothing left." P5	.
	Hope/positivity		"keeping positive. I think	you need people around	"certain cancers have been	my attitude right the way through	.

			that's one of the most important things." P2	you that, even if they don't think it, they need to show it that they've got a positive attitude P3;	successfully treated haven't they? For a long time!" P4	was that I was going to beat it P5	
Social	**Relationships**		"Support networks don't mean very much to me I'm afraid" P2	"A few people that, erm, where you thought you were closer to, as you say, they sort of, backed off a bit. But others were very supportive." P3	"Certain close friends find it very difficult and they back off" P4	I couldn't speak to him because of the way I was, within myself P5	I didn't want to make contact cos I just couldn't cope cos I was up to here P6
Support		After that initial	"I don't actually	.	.	.	"I even went to

		diagnosis, I had to go and make my own follow up P1	agree with you about support groups you see, because, I've been to one and found it to be one of the most depressing experiences of my life" P2				Boots chemist for some help one Saturday morning, cos I was desperate" P6
	Contact with hospital	"I was coming in here every three weeks or every couple of months. And that was really helpful because you're constantly seeing the same people, who are experts in their field	.	.	"And then you get fired off at the end. You're at home aren't you?" P4	"it's needing to know there is somebody" P5	.

		all the time" P1					
	Psychological	we do perhaps need to have a separate clinic, not necessarily in here but somewhere else in the hospital or somewhere else where you can come and talk to us about it P1	I honestly can't see how it would help me in the slightest. It would just be a waste of my time P2	"they don't really advertise it to you much" P3	"I'd rather have somebody prescribe something than deep, psycho, self analysis" P4	"I don't think the support is there" P5	.
	Reassurance	both of them independently said, if you're going to get cancer, get this one P1	.	.	.		
	For family	She was pretty upset about it P1	.	"the family suffer worse" P3	.		
Practical		this is where you	"You do need	you could help	"They do go to	"dealing with	if only they had

		need... someone like Macmillan to help you P1	someone who knows the system to help you" P2	at home but just... didn't feel like it. Just didn't seem to have... the energy P3	quite a lot of effort don't they to find out who you live with, who's there, what your properties like" P4	those sorts of people (DWP) was difficult and, erm, it would have been very difficult to get anything in writing from anyone here I feel" P5	a little side room for the days that you, for the days that people are really sick P6
Information	**Delivery**		"he went through it all and explained it all to me and what was going to happen" P2	words of one syllable… and plain, simple English P3	.	that's fine with me, you know that's the way I want the information P5	.
	Personalised	they also give you the five to ten year prognosis, which is, not very helpful	there has got to be a happy medium P2	.	when you first start you get all these generic leaflets on you	"relevant to your diagnosis, that's very important" P5	.

		when you're forty-something P1			know, how do you get a wig, I don't need a wig, what's going to happen if, what's the likely side effect. P4		
	Availability		I find it very difficult to understand the system in all honesty P2	"there was nothing that the doctor could say, this is what you've got, right now this will explain everything" P3	"I think you get as much information as you, as you ask for" P4	.	yes it's a guideline really and having... a criteria to... what you, what you should put up with P6
Haematology	**Other's understanding**	"when I say to people I've got lymphoma, they say,	.	.	"they think cancer's cancer, and it isn't is	.	"My GP again, gave me tramadol which

		what's that then?" P1			it?" P4		I couldn't take, and he said he couldn't prescribe anything else without a lot of, without a lot of research on what I'd already got" P6
	Differences	"I'm in remission and, you know, hope to be so for as long as possible but, there's no outward signs. Now, if you've had aggressive breast cancer and, for instance, you've had a mastectomy…	.	.	.	.	"if you'd had breast cancer it would have been fine" P6; "but once, with breast cancer, once they take it away it makes a big difference" P6

		and your body image changes. Whereas here there isn't much to take away, it's all, it's more medicine as opposed to surgery and it's more like diabetes that's controlled" P1					
	Support available					I think to have someone like that on the ward (support nurse), who is not dealing with chemotherapy and all the rest of it P5	"Now if you've got cancer, the Macmillan nurses are superb" P6
Medical	**Communication**			"even though they kept	"Liverpool knew exactly what the	.	"I said I'm not having any

				explaining things… they use big words and names of stuff. If it was written down you'd probably be able to take it in easier" P3	people had done here, people here knew what Liverpool had done" P4		more, I've only come to see Dr Lee. Anyway, next thing he comes and says you've got another six" P6
	Cognition					memory's gone, concentration's a problem P5	I can't concentrate long enough, which after 50 years is a bit difficult P6
	Interactions with HCPs	the butcher of the (location) P1	.	"I think I just got me knickers in a right twist because they	they have a different bedside manner don't they? P4	it's the determination of the staff, I felt that they were going about	it was done jokingly but inside you're god how much longer? P6

				kept, oh, oh this is wrong…" P3		things in such a way that just added to my own determination P5	
	Key worker	your key worker thing, but that was very interesting and very important P1	Seeing the same person every time so you don't have to explain everything else to them again P2	.	.	.	"I just feel if only I had somebody like Laura, like Dee, somebody who would go through things with you… when you're desperate. That's what we're short of." P6
	Staff	know what they're	"I think the staff	you're not	"Absolutely	the staff here	I can't speak

		doing, the staff here do it all day every day P1	there were fantastic" P2	anything special but it is a nasty thing to have and they used to, really, put you at your ease actually P3	brilliant. Really high emotional intelligence" P4	have been absolutely phenomenal P5	highly enough of them P6
Physical		"as you get older the physical needs and issues change regardless of how well you are" P1	"I was aware that I was very tired at the time, and since then it's not really made much difference to me" P2	"putting it straight forward, I felt absolutely knackered" P3	"that's the main need, trying to keep yourself strong enough when you've really had no appetite" P4	Yes, the, the exhaustion does continue. I find that I can't do what I used to. P5	it's the fatigue, it's doing things P6
Cancer	**Uniqueness**	"I don't know if people who haven't experienced that can quite understand" P1	.	.	.	.	I think, you don't know how hard it is P6

	Perceptions	people don't expect you to die anymore P1	I don't know what people expect of you when you're ill, I'm not one to be going around moping and groaning P2	“a lot of people think as soon as you’ve mentioned cancer, they think god, we’ll be burying him soon” P3	“everyone talks about, again, you know, the media, fighting… battling cancer, fighting cancer, so and so’s beaten cancer four times. Well, I… I don’t know what that means really.” P4	.	
	Giving something back	I go along to show people that it's not just people in their 70s that suffer from this P1	.	.	I did this whole school assembly once, I just said to all the kids, look... I woke up one morning	.	Certainly if I could go and... give support, I would do. P6

					and had a lump the size of an orange on my shoulder P4		
Identity	**Appearance**			"I think it's worse for a woman than it is for a fella" P3	"That was the biggest thing I was worried about, body image" P4	.	"I just felt a freak" P6
	Sense of self	I think, sometimes, if you've had cancer, people see you as a cancer sufferer, or a recovering cancer sufferer, rather than as John or Fred or Mary P1	"you get into that… cancer… sufferer" P2	.	even at the time I was pretty touchy about it P4	"I had the fishing but that didn't matter, just looking at the world going past and realising that, yeah I am still part of it" P5	.
	Respect	"I think sometimes, if you've had cancer, people see you as a	.	"I always felt that I was being treated	"you get treated differently though" P4	"I found the respect as an individual rather	.

		cancer sufferer, or a recovering cancer sufferer, rather than as John or Fred" P1		with the greatest respect on the ward" P3		difficult" P5	
Work		"I think, gaining employment, after diagnosis… is something that is potentially more difficult" P1	"It depends who you work for" P2	"Erm (pause) special work colleagues I've got, I had a litre bottle of single malt whisky to open at the end of 5 years (all laugh), I'll keep that for then" P3	"I was just thinking, right, I'm gonna be off work now, for 6 months on full pay, 6 months on half pay and just dealt with all of the practical things" P4	"A fear of returning to work" P5	.
Barriers to support	**Feel unable to ask for help**		"When you're not used to doing that, and perhaps not comfortable	.	"I think the support is there if you, you want it. You just ask.	if I had a problem, there was no way I could let them	"They say you can ring the ward but you don't want to

			with doing that" P2		But I think sometimes, do you not think people are afraid to ask? In case, because everyone's busy, I think some people get it in their head, oh I can't, I'd better not ask in case they're busy" P4	know P5	ring the ward because you've got bad arms" P6
	Clinics too busy	"I don't know if you've been to clinic here recently, there's a hundred people out there" P1	I kept saying that I, I'm sorry, I don't like troubling you P2	.	.	I don't think the support is there. And the reason for that again is down to time. P5	"That's the problem, to realise just how busy they are" P6
	Psychosocial	"he said, because	.	.	"I was just	this front that	"But I was

	not discussed	we can only give you a short amount of time because there's so many people who need to be seen through this clinic, we haven't touched on the psychological apsects of what we're doing" P1			sitting there listening, reading my paper, being as jolly as possible when someone came round so, maybe they thought, well this is a guy who doesn't seem to be presenting as anything" P4	you put up... they don't know how to get through P5	reluctant because... pride. Erm, but yes I think you cover a lot up." P6
	Physical more important					"I was so grateful and so lucky that in my first session of chemo all I got… And to see other people there…	.

						how can I be dragging nurses away from them to deal with the way I was thinking about things, not feeling, but thinking about things? It just didn't come into the equation." P5	
	Not important enough					"his time is far too valuable to be doing that. So, again, you tend not to talk through the problems you	.

						have with him." P5	
Understanding experiences	**Comparisons with others**	I went along to my first support group at the Lymphoma Association and there's a lady there who was diagnosed wih NHL 18 years ago P1	I've been very fortunate in my life, I've hardly ever been ill, so, I accepted that it was my turn, if you like, to be ill P2	I think I was very lucky P3	.	to see him deteriorate over the next three months and die... err, was horrendous P5	people don't seem to get a lot of pain but... erm, pain in your arms I found was dreadful P6
Control	**Taking control**	that's when I referred myself to (Dr), because they couldn't find me a haematologist within about, two months, which I didn't think was good enough P1	"I went for a number two (hair cut), because I thought I'm not going to go around looking like tufty" P2	you've just got to get on with it P3	the doctors will go in and sort it out, that was my attitude P4	took on the what will be will be type attitude and put all my faith in the people here P5	"Mind over matter" P6
	Feeling in control as	I've done all this, there's stacks of	But you also know what it is	you get a bit anxious about	I did feel as if we knew exactly	If it's... cancer... so what? I know	if you knew, you can deal

	coping mech	paper in my office at home P1	P2	knowing everything that's going on P3	where we were and what the next step was, and broadly what the significance of every part of the intervention was really P4	where I am. P5	with it can't you P6
Environment		"we do need to perhaps have a separate clinic, not necessarily in here but somewhere else in the hospital or somewhere else where you can come and talk to us about it" P1	"I really didn't want to go back there, it depressed me no end that… experience" P2	once I was out of there, I was back to normal P3	very little of the conversation on the ward was about your condition P4	I always liked to be in the same place for my chemo P5	.
Personal		it kind of makes you	it concentrates	.			

changes		a different person at the end of it P1	your mind a little bit P2				

Appendix 8: Patient Information Flyer

INFORMATION FLYER: Experiences of Living with Cancer – The Patient's Perspective

What is the study about?

A research team at the University of Chester are carrying out some research that is investigating unmet psychosocial needs in Haematological Cancers and how people adjust to life after they receive their diagnosis. Psychosocial needs are all of a person's non-medical needs, for example wanting someone to talk to about your feelings, changes in the way that you might feel about yourself or more practical issues such as travel to and from the hospital.

At present, the team at the university are looking to recruit participants to take part in focus groups, that is group interviews, to discuss what their psychosocial needs were at the time of the diagnosis, during their treatment and after the treatment has ended.

The aim of this research is to gain a clearer understanding of what the priorities are relating to psychosocial need for people who have been diagnosed with a haematological cancer with the hope that this knowledge will make it easier to meet other patient's needs in the future.

What will happen if I indicate that I would like to be contacted by someone at the University of Chester?

If you indicate on the consent form that you would like to be contacted by someone at the University of Chester, then you would be agreeing to allow someone at the university to have your name and address so that an information pack could be sent to you by post.

Saying yes to this does not mean that you are agreeing to take part in the study. It simply means that you are happy for more information to be posted out to you. If, when you read the information pack you decide not to take part that is not a problem. You will not need to do anything further and the research team will remove your contact details from their records. Whether or not you decide to take part in the study will have no impact upon your treatment at the Countess of Chester Hospital.

If you have any questions, please speak to a member of the team on the Haematology Oncology ward.

Appendix 9: Consent Form

Project Title: Living with Cancer – Patient perspectives.

Contact details:

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PLEASE INITIAL BOX

1. I confirm that I have read and understood the information sheet and that I have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. I understand that if I leave part-way through the focus group, then my data may still be used. ☐

3. I agree to take part in the above study. ☐

4. I agree to the focus group being audio recorded. ☐

5. I agree to anonymised quotations being used in publications. ☐

6. I understand that information shared within the ☐

focus group is to be treated as confidential.

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 10: Study Invitation Letter

INVITATION TO TAKE PART IN A FOCUS GROUP –

'Living with Cancer – Patient perspectives'

Dear ,

I am writing to you from the University of Chester. I am a PhD student carrying out research looking the unmet psychosocial needs experienced by people with haematological cancers. I am writing to invite you to take part in a focus group that will be running in Chester. The aim of the focus groups is to learn people's opinions regarding their experiences of need during their illness and what they feel is important at this time. Your views and ideas would be very valuable and will be used to help change and improve how needs are met for people with haematological cancer in the future.

I have included an information sheet that will hopefully answer all of the questions that you may have about the study.

If you can, please take a moment to read through the information that is attached and if you feel that this is something that you would be interested in being involved in, then please return the participant consent form in the pre-paid envelope. Should you wish to take part, then details of when and where the focus group will be held will be sent to you.

I would like to thank you for taking the time to read this later and the accompanying information,

Yours sincerely,

Brooke Swash

University of Chester,
Department of Psychology,
Chritchley Building,
Parkgate Road,
Chester,
CH1 4BJ

Appendix 11: Patient Information Sheet

INFORMATION SHEET

Study Title: Living with Cancer – Patient and professional perspectives.

You are being invited to take part in a research study. Before deciding whether or not you would like to take part, it is important that you understand why the study is being done and what your participation would involve. Please take some time to read the following information carefully.

What is the purpose of the study?

Receiving a diagnosis of cancer and all that comes after this is often a very distressing time. Unmet psychosocial needs are all of the non-medical needs that may arise concerning a person's practical, emotional, psychological and supportive needs. This can include anything from wanting someone to talk to about how you are feeling to more practical concerns such as childcare or transport to and from the hospital. Existing research shows that meeting these psychosocial needs can be really important for helping a person get through such a difficult time.

This study aims run a series of focus groups with people who either have a diagnosis of a haematological cancer or who are now in remission and with the healthcare professionals who care for them to find out more about the unmet psychosocial needs that are the most important and relevant to them.

Why have I been invited to take part?

During an appointment with your medical team at the Countess of Chester Hospital, you were given some information about this study and indicated that you were happy to be contacted with more information regarding the study. If you have changed your mind about wanting to take part, then please refer to the next section.

Do I have to take part?

No. It is entirely up to you whether or not you would like to take part in this study. Choosing to take part will have no impact upon any further treatment or follow up that you may have scheduled at the Countess of Chester hospital and details of your participation are completely confidential. If you decide that you do not wish to participate then the research team will remove your contact details from their records and you will not be contacted again.

If you do decide that you would like to take part and then change your mind, then you are free to withdraw. If you start to take part in the focus group but then feel that you would like to leave, that is OK too but please be aware that we may still analyse the part of the discussion that you have already taken part in. Unfortunately, we can't avoid this as it may impact on our ability to include what other participants have said during the discussion. Also, you do not have to answer any question that you don't want to.

What will taking part involve?

If you do decide to take part then you will be invited to attend a focus group. Hopefully we will be able to coincide the timing of the focus groups with participant's existing clinic visits at the Countess of Chester Hospital. The purpose of the focus group will be to allow people to talk about their needs throughout their illness and to discuss the importance of different needs. We will be focussing on the psychosocial aspects of needs rather than the medical issues. If at any point you do not wish to answer a question then you are under no obligation to do so.

The focus groups will be audio recorded so that transcripts of the conversations can be written up afterwards. The transcripts of the focus groups will then be analysed to determine which psychosocial needs have been identified during the focus groups and which were felt to be the most important.

What are the possible benefits of taking part?

There will be no direct benefits to you from taking part. What this study aims to do is to improve our understanding of unmet psychosocial needs in haematological cancer patients so that these needs can be better met for others in the future.

What are the possible disadvantages of taking part?

While we hope that these focus groups will be a positive experience that will allow you to look back and reflect on your experiences with others, we also understand that talking about being ill and what that was like with other people may be upsetting. Before agreeing to take part, you should consider whether you feel that discussing your illness and your needs during this time is something that you would feel able to do.

There are the time implications of taking part, it is expected that the focus group will last approximately 60 minutes, although it may take a little longer. If we are unable to hold the focus group on a day when you are visiting the hospital for a clinic visit, then we will reimburse your travel expenses.

What should I do if I want to take part?

A participant consent form has also been included in this pack. If you would like to take part, please complete this form and return it in the envelope provided.

Confidentiality

The data provided by you will only be used for the purposes of this study. Information will be stored securely and confidentially and in any reports, papers or write ups you will remain entirely anonymous. All data will be stored in accordance with the Data Protection Act and University Research policies. Once analysis is completed, the transcripts of the focus groups will be kept on a password protected CD in secure university archives. Paper based documents will also be kept securely within the university. All archived research data will be confidentially destroyed after ten years.

Who is organising and funding the study?

The research is being organised and carried out by a research team based at the University of Chester. The lead researcher is Brooke Swash although the team also includes Dr Nick Hulbert-Williams and Professor Ros Bramwell at the University of Chester and Dr Edwin Lee at the Countess of Chester Hospital. The research is

being funded by both the University of Chester and the Countess of Chester Hospital NHS Foundation Trust.

Who has reviewed this study?

Ethical approval has been sought from both the University of Chester and NRES (NHS ethics). Local research governance approval has been sought from the Countess of Chester NHS Foundation Trust.

What if something goes wrong?

If you have any concerns or complaints regarding this study, please contact the Head of Department, Department of Psychology, University of Chester, or the Patient Advice and Liaison Service (PALS) at the Countess of Chester Hospital.

What will happen to the results of the study?

This study is part of a PhD project being completed at the University of Chester and will be written up as part of the thesis. In addition, the results will be written up as a research paper that will be submitted for publication within health psychology and cancer-related academic journals. In all cases, participants will remain anonymous. If you would like a summary of the results, please contact Brooke Swash via the contact details below.

Contact details for further information:

Brooke Swash

University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
b.swash@chester.ac.uk

Dr Nick Hulbert-Williams

University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
n.hulbertwilliams@chester.ac.uk

I would like to thank you for taking the time to read this information sheet. Please keep this sheet for future reference.

Appendix 12: Demographic Questionnaire

Please complete the following questionnaire by circling the appropriate answer:

1. Are you: Male Female

2. What is your age range?: 18-30 31-40 41-50
   51-60 61-70 71-80
   81-90 90+

3. Which of the following best describes you:

   Employed full-time Employed part-time Self-employed Retired Full-time education
   Other Not employed (seeking work)
   Not employed (ill health)

4. Do you care for any dependants?: One Two Three Three+

5. Are you:

   White Black-African Black-Caribbean
   Asian-Indian Asian-Pakistani Asian-Bangladeshi
   Chinese Other (please specify)……

6. What type of cancer were you diagnosed with?.....

7. How long ago did you receive your diagnosis?.....

8. What treatments did you receive?.....
.....

Thank You

Appendix 13: Ethical approval letter

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru
Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys
The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

North Wales REC (Central & East)
G1/G2 Croesnewydd Hall
Croesnewydd Road
Wrexham Technology Park
Wrexham LL13 7YP
Telephone : 01978 726377
E-mail : tracy.biggs@wales.nhs.uk
Website : www.nres.nhs.uk

03 January 2013
Miss Brooke E Swash
PhD Student
University of Chester
University of Chester, Department of Psychology,
Chritchley Building, Parkgate Road,
Chester
CH1 4BJ

Dear Miss Swash
Study title: Unmet psychosocial needs and their role in psychological adjustment to a diagnosis of haematological cancer: A comparison between treatment subgroups.
REC reference: 12/WA/0366
IRAS project ID: 108725
Thank you for your letter of 2 January 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our
letter dated 21 December 2012

Documents received
The documents received were as follows:
Document Version Date
Participant Information Sheet 3 02 January 2013
Approved documents
The final list of approved documentation for the study is therefore as follows:
Document Version Date
Covering Letter 19 November 2012
Covering Letter 12 December 2012
Evidence of insurance or indemnity 09 July 2012
GP/Consultant Information Sheets 1 13 November 2012
GP/Consultant Information Sheets 1 13 November 2012
Investigator CV 19 November 2012
Investigator CV
Investigator CV
Letter from Sponsor 13 November 2012
Letter of invitation to participant 2 07 December 2012
Participant Consent Form 1 13 November 2012

Participant Information Sheet 3 02 January 2013
Protocol 2 12 December 2012
Questionnaire: HADS
Questionnaire: Mini-MAC Scale
Questionnaire: QLQ-C30
Questionnaire: SCNS-SF34
Questionnaire: SDI
Questionnaire: Brief COPE
Questionnaire: Benefit Finding
Questionnaire: Survey of cancer patient's needs
Questionnaire: Demographic Questionnaire 1 19 November 2012
REC application 1 21 November 2012
Response to Request for Further Information 12 December 2012
Summary/Synopsis 1 13 November 2012
You should ensure that the sponsor has a copy of the final documentation for the study. It is
the sponsor's responsibility to ensure that the documentation is made available to R&D
offices at all participating sites.

12/WA/0366 Please quote this number on all correspondence

Yours sincerely
Mrs Tracy Biggs
Committee Coordinator

E-mail: tracy.biggs@wales.nhs.uk

Copy to: Mark Helsdon, University of Chester

Ms Sheila Williams, Countess of Chester Hospital NHS Foundation Trust

Appendix 14: Participant Information Sheet

Adjusting to a diagnosis of cancer: Treatment group differences.

You are being invited to take part in a research study. Before deciding whether or not you would like to take part, it is important that you understand the purpose of the study and what taking part would involve. Please take some time to read through the following information.

What is the purpose of this study?

Receiving a diagnosis of cancer can sometimes be difficult and upsetting. Many people will find ways of managing and of coping with illness, however, for some people it will have a negative impact upon their life and their sense of wellbeing. This study aims to assess how people respond to their diagnosis, and how this changes over time in people who have been recently diagnosed with haematological cancer. We are trying to better understand the factors that cause distress and who is most at risk of experiencing distress after their diagnosis. Having a greater understanding of how people adjust to a new diagnosis would mean that in the future we will be better able to prevent people from experiencing distress by providing more efficient support to those who need it most.

Why have I been invited to take part?

We are recruiting people from several hospitals in the North West of England and North Wales who have been recently diagnosed with haematological cancer to take part in this survey about adjusting to your diagnosis.

Do I have to take part?

No. It is entirely up to you whether or not you would like to take part in this study. Choosing to take part will have no impact upon any further treatment or follow up that you may have scheduled at your hospital and details of your participation are completely confidential.

If you do decide to take part and then later change your mind, then you are free to withdraw from the study at any time.

What will taking part involve?

If you do decide to take part, then you will be invited to complete a questionnaire on two separate occasions that will contain questions about your life and how things might have changed upon receiving your diagnosis. We will post out the first questionnaire as soon as you agree to take part in this study and the second questionnaire will be posted out to you three months later. The questionnaire can be filled in in your own time, at home.

Please be aware that the questionnaire you will be asked to complete contains questions that were developed for general cancer groups and therefore some questions may not be directly relevant to your situation. If you feel that any of the questions asked are not relevant to you, then simply highlight as not relevant. This is fine and will still be very useful to us when we analyse the results of this study.

We will be asking for your GP contact details on the demographic questionnaire included within this information pack. This is so that we can inform your GP that you are a participant in this study. We will also be contacting your GP before we send out the second questionnaire to confirm continued eligibility.

We may require access to your medical records. This is to allow us to confirm the diagnosis and treatments received by participants. We will be accessing your records for demographic data only and this will be treated with the utmost confidentiality.

What should I do if I want to take part?

A participant consent form has been included in this pack. If you would like to take part, please complete the form and return it in the envelope provided.

Confidentiality

The data provided by you will only be used for the purposes of this study. Information will be stored securely and confidentially and in any reports, papers or write ups you will remain entirely anonymous. All data will be stored in accordance with the Data Protection Act and with University Research policies. All electronic data and analysis will be maintained on secure university computers. Once analysis is completed, data will be kept on a password protected CD in secure university archives. All paper documents will also be kept securely within the university. All archived research data will be confidentially destroyed after ten years.

What happens if my questionnaire indicates that I might benefit from more help from my hospital's support services?

In rare cases, a participant's returned questionnaire may indicate that they are experiencing considerable distress as a result of their illness. If this were to happen, then the research team would have a duty of care to ensure that the participant is offered some extra support. The research team would therefore use the identification number at the top of your questionnaire to find the participant's name and contact details. The research team would then get in touch with the Consultant at the hospital to discuss how to support the participant. Further support could range from informal advice from your Consultant to a referral to your hospital's psychological support services.

Who is organising and funding the study?

The research is being organised and carried out by a research team based at the University of Chester. The lead researcher is Brooke Swash although the team also includes Dr Nick Hulbert-Williams and Professor Ros Bramwell. The research is being funded by both the University of Chester and the Countess of Chester Hospital NHS Foundation Trust.

Who has reviewed this study?

Ethical approval has been sought from both the University of Chester and by the North Wales REC (Central and East). Local research governance approval has been sought at each of the participating hospitals.

What if something goes wrong?

If you have any concerns or complaints regarding this study, please contact the Head of Department, Department of Psychology, University of Chester, or the Patient Advice and Liaison Service (PALS) at your treating hospital.

What will happen to the results of the study?

This study is part of a PhD project being completed at the University of Chester and will be written up as part of the thesis. In addition, the results will be written up as part of a research paper that will be submitted for publication within relevant academic journals. In all cases, participants will remain anonymous. If you would like a summary of the results, please contact Brooke Swash via the contact details provided below.

Contact details for further information:

Brooke Swash

University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
b.swash@chester.ac.uk

07827807466

Dr Nick Hulbert-Williams

University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
n.hulbertwilliams@chester.ac.uk

I would like to thank you for taking the time to read this information sheet. Please keep this sheet for future reference.

Appendix 15: Participant Consent Form

Study - Adjusting to a diagnosis of cancer: Treatment group differences.

Contact details:

Brooke Swash
University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
b.swash@chester.ac.uk
01244 5133179

Dr Nick Hulbert-Williams
University of Chester,
Department of Psychology,
Critchley Building,
Parkgate Road,
Chester,
CH1 4BJ
n.hulbertwilliams@chester.ac.uk

PLEASE INITIAL BOX

7. I confirm that I have read and understood the information sheet and that I have had the opportunity to ask questions. ☐

8. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐

9. I agree to take part in the above study. ☐

☐

10. I understand that if my questionnaire indicates any cause for concern, then the research team may contact my hospital in order to discuss this further. ☐

☐

11. I consent to allow the research team access to key information about my diagnosis and treatment

from my medical records.

12. I consent to allow the research team to contact my GP regarding my involvement in the study.

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 16: Debrief Sheet

Adjusting to a diagnosis of cancer: Treatment group differences.

Dear ……,

On behalf on the research team, I am writing to thank you for taking the time to participant in our research study. You contributions are greatly valued. You are not required to do anything further or to provide any further information.

If you would like to receive a general summary of the results then please do let us know and we will be happy to provide this for you. At present, the data generated by the questionnaires is being analysed and we are confident that the information that you and your fellow participants were able to share with us will greatly contribute towards our understanding of psychological health and wellbeing after receiving a cancer diagnosis.

I would like to assure you that all of your personal details and the information that you gave us will be treated confidentially and all identifying information will be removed in our study write up.

Please feel free to contact us if you have any further questions about the study. Any questions or concerns that you may have relating to your medical condition or treatment would be best addressed to your GP or the cancer team at the hospital where you were treated.

Cancer can cause a great deal of distress and confusion both at the time of diagnosis and even after treatment has finished. If you think that talking to someone about your experiences may be of benefit to you, the following telephone numbers might be helpful:

Macmillan Cancer Support: 0808 808 0000

Cancer Help UK: 0808 800 4040

The Samaritans: 08457 909090

Once again, I would like to thank you for taking part in our research. We wish you all the very best in the future.

Brooke Swash

Appendix 17: Letter to GP

Dear [GP name],

I am writing to inform you that your patient, [insert name], has consented to take part in a research study, **'Adjusting to a diagnosis of cancer: Treatment group differences.'**, being run by the University of Chester. You do not need to do anything at this time.

Patient name:

This study is investigating psychological adjustment to receiving a diagnosis of haematological cancer, forming comparisons between those receiving active treatment and those monitored on a 'watch and wait' regime.

There will be no changes to your patient's treatment or follow up as a result of their participation in our study. Participation will involve the completion of a questionnaire both at the time of diagnosis and at a three month follow up.

In order to satisfy ethical requirements, we will need to contact you prior to the completion of the follow up questionnaire to confirm that your patient is still eligible to take part.

If you have any questions regarding the study, please do not hesitate to get in touch.

With best wishes,

Brooke Swash

Gladstone Fellowship Psychology PhD Student
University of Chester
Department of Psychology
Chritchley Building
Parkgate Road
Chester
CH1 4BJ

Phone: 01244 513179
Email: b.swash@chester.ac.u

Appendix 18: Follow-up Letter to GP

Dear [GP name],

Following on from my letter dated [insert date] regarding [patient name] involvement in the study **"Adjusting to a diagnosis of cancer: Treatment group differences",** I am writing to you to confirm this person's continued eligibility to take part in this study. We require that participants are alive and have a life expectancy of over two weeks.

Please let us know if you feel that this patient's continued involvement in this would not be appropriate and the reason(s) for this.

Potential reasons for exclusion:

- This person is not expected to survive more than two weeks;
- This person is too ill to take part;
- This person is known to have died;
- Any other reason.

With best wishes,

Brooke Swash

University of Chester,
Department of Psychology,
Chritchley Building,
Parkgate Road,
Chester,
CH1 4BJ

b.swash@chester.ac.uk
01244 513179

……

……

(Please remove this slip and return in the pre-paid envelope.)

Patient name:

This person remains eligible for inclusion in the study 'Adjusting to a diagnosis of cancer: Treatment group differences'.

☐ Yes

☐ No

Appendix 19: Microsoft Word version of study questionnaire (as completed by participants)

Please complete the following questionnaire by putting an X in the box for the appropriate answer:

Are you: Male ☐ Female ☐

What is your age range: 18-30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐

61-70 ☐ 71-80 ☐ 81-90 ☐ 90+ ☐

Which of the following best describes you: Employed full-time ☐ Self-employed ☐

Full-time education ☐ Not employed (ill health) ☐ Employed part-time ☐

Retired ☐ Not employed (seeking work) ☐ Other ☐

Do you care for any dependents?: No ☐ One ☐ Two ☐ Three ☐ Three+ ☐

Are you: White ☐ Black-Caribbean ☐ Asian-Pakistani ☐ Chinese ☐

Black-African ☐ Asian-Indian ☐ Asian-Bangladeshi ☐ Other ☐

What type of cancer were you diagnosed with?……

How long ago did you receive your diagnosis?.....

Have you received treatment for your diagnosis?

Yes ☐ Please specify…….

No, I am being monitored on 'Watch and Wait' ☐

Please could you provide us with your GP's name and address:

……

……

……

(SCNS SF34) To help us plan better services for people diagnosed with cancer, we are interested in whether or not need which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. <u>Put a X in the box which best describes whether you have needed help with this in the last month.</u> There are five possible answers:

1. **Not applicable – This was not a problem for me as a result of having cancer.**
2. **Satisfied – I did need help with this, but my need was satisfied at the time.**
3. **Low need – This item caused me concern or discomfort. I had little need for additional help.**
4. **Moderate need – This item caused me concern or discomfort. I had some need for additional help.**
5. **High need – This item caused me concern or discomfort. I had a strong need for additional help.**

	1	2	3	4	5
Pain					
Lack of energy / tiredness					

Feeling unwell a lot of the time					
Work around the home					
Not being able to do the things you used to					
Anxiety					
Feeling down or depressed					
Feelings of sadness					
Fears about the cancer spreading					
Worry that the results of treatment are beyond your control					
Uncertainty about the future					
Learning to feel in control of your sitation					
Keeping a positive outlook					
Feelings about death and dying					
Changes in sexual feelings					
Changes in your sexual relationships					
Concerns about the worries of those close to you					
More choice about which cancer specialists you see					
More choice about which hospital you attend					
Reassurance by medical staff that the way you feel is normal					
Hospital staff attending promptly to your physical needs					
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs					
Being given written information about the important aspects of care					

Being given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home					
Being given explanations for those tests for which you would like explanations					
Being adequately informed about the benefits and side-effects of treatments before you choose to have them					
Being informed about your test results as soon as feasible					
Being informed about cancer that is under control or diminishing (that is, remission)					
Being informed about things you can do to help yourself get well					
Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it					
Being informed about sexual relationships					
Being treated like a person not just another case					
Being treated in a hospital or clinic that is as physically pleasant as possible					
Having one member of staff with whom you can talk about all aspects of your condition, treatment and follow-up					

(HADS) This questionnaire is designed to help us know how you are feeling. Read each one and tick the reply which comes closest to how you have been feeling IN THE PAST WEEK.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or wound up:

Most of the time ☐ *A lot of the time* ☐ *From time to time* ☐ *Not at all* ☐

I still enjoy the things I used to:

Definitely as much ☐ *Not quite as much* ☐ *Only a little* ☐ *Hardly at all* ☐

I get a sort of frightened feeling as if something awful is about to happen:

Very definitely and quite badly ☐ *Yes, but not too badly* ☐

A little, but it doesn't worry me ☐ *Not at all* ☐

I can laugh and see the funny side of things:

As much as I always could ☐ *Not quite so much now* ☐ *Definitely not so much n* ☐

Not at all ☐

Worrying thoughts go through my mind:

A great deal of the time ☐ *A lot of the time* ☐ *From time to time, but not often* ☐

Only occasionally ☐

I feel cheerful:

Not at all ☐ *Not often* ☐ *Sometimes* ☐ *Often* ☐

I can sit at ease and feel relaxed:

Definitely ☐ *Usually* ☐ *Not often* ☐ *Not at all* ☐

I feel as if I am slowed down:

Nearly all the time ☐ *Very often* ☐ *Sometimes* ☐ *Not at all* ☐

I get a sort of frightened feeling like "butterflies" in the stomach:

Not at all ☐ *Occasionally* ☐ *Quite often* ☐ *Very often* ☐

I have lost interest in my appearance:

Definitely ☐ *I don't take as much care as I should* ☐ *I may not take quite as much care* ☐

I take just as much care ☐

I feel restless as if I have to be on the move:

Very much indeed ☐ *Quite a lot* ☐ *Not very much* ☐ *Not at all* ☐

I look forward with enjoyment to things:

As much as I ever did ☐ *Rather less than I used to* ☐ *Definitely less than I used to* ☐

Hardly at all ☐

I get sudden feelings of panic:

Very often indeed ☐ *Quite often* ☐ *Not very often* ☐ *Not at all* ☐

I can enjoy a good book or radio/TV programme:

Often ☐ *Sometimes* ☐ *Not often* ☐ *Very seldom* ☐

(EORTC QLQ-C30) We are interested in some things about you and your health, please answer all questions yourself by ticking the response that best applies to you, there are not 'right' or 'wrong' answers.

	Not at all	A little	Quite a bit	Very much

Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or a suitcase?				
Do you have any trouble taking a long walk?				
Do you have any trouble taking a short walk outside of the house?				
Do you need to stay in bed or a chair during the day?				
Do you need help with eating, dressing, washing yourself or using the toilet?				
DURING THE PAST WEEK				
Were you limited in doing either your work or other daily activities?				
Were you limited in pursuing your hobbies or other leisure time activities?				
Were you short of breath?				
Have you had pain?				
Did you need rest?				
Have you had trouble sleeping?				
Have you felt weak?				
Have you lacked appetite?				
Have you felt nauseated?				
Have you vomited?				
Have you been constipated?				
Have you had diarrhoea?				
Were you tired?				

Did pain interfere with your daily activities?				
Have you had difficulty in concentrating on things, like reading a newspaper or watching the television?				
Did you feel tense?				
Did you worry?				
Did you feel irritable?				
Did you feel depressed?				
Have you had difficulty remembering things?				
Has your physical condition or medical treatment interfered with your family life?				
Has your physical condition or medical treatment interfered with your social activities?				
Has your physical condition or medical treatment caused you financial difficulties?				

For the following questions please tick the number that best applies to you:

How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor Excellent

How would you rate your overall quality of life during the past week:

1 2 3 4 5 6 7

Very poor Excellent

A number of statements are given below which best describe people's reactions to having cancer.

Please tick the box to the right of each statement, indicating how far it applies to you at present.

	Definitely does NOT apply to me	Does NOT apply to me	Applies to me	Definitely applies to me
At the moment I take one day at a time				
I see my illness as a challenge				
I've put myself in the hands of God				
I feel like giving up				
I feel very angry about what has happened to me				
I feel completely at a loss about what to do				

It is a devastating feeling				
I count my blessings				
I worry about the cancer returning or getting worse				
I try to fight the illness				
I distract myself when thoughts about my illness come into my head				
I can’t handle it				
I am apprehensive				
I am not very hopeful about the future				
I feel there is nothing I can do to help myself				
I think it is the end of the world				
Not thinking about it helps me cope				
I am very optimistic				
I’ve had a good life and what’s left is a bonus				
I feel that life is hopeless				
I can’t cope				
I am upset about having cancer				
I am determined to beat this illness				
Since my cancer diagnosis I now realise how precious life is and I’m making the most of it				

I have difficulty believing that this happened to me				
I make a positive effort not to think about my illness				
I deliberately push all thoughts of cancer out of my mind				
I suffer great anxiety about it				
I am a little frightened				

(Benefit Finding) Cancer patients sometimes feel that having cancer makes contributions to their lives, as well as causing problems. Indicate how much you agree with the following.

Having had cancer…

	Not at all	A little	Moderately	Quite a bit	Extremely
Has lead me to be more accepting of things					
Has taught me to adjust to things I cannot change					
Has helped me take things as they come					

Has brought my family closer together					
Has made me more sensitive to family issues					
Has taught me that everyone has a purpose in life					
Has shown me that all people need to be loved					
Has made me realise the importance of planning for my family's future					
Has made me more aware and concerned for the future of all human beings					
Has taught me to be patient					
Has lead me to deal better with stress and problems					
Has lead me to meet people who have become some of my best friends					
Has contributed to my overall emotional and spiritual growth					
Has helped me to become more aware of the love and support available from other people					
Has helped me realise who my real friends are					
Has helped me become more focussed on priorities, with a deeper sense of purpose in life					
Has helped me to become a stronger person, more able to cope effectively with future life challenges					

(SDI 21) Sometimes people who have, or have had cancer find that they have a number of everyday difficulties to cope with following their diagnosis. These may be to do with things like their family life, social activities, finances and work. We are interested in finding out what difficulties and problems patients have to cope with. Only when we find out the range and depth of these difficulties can we begin to make plans for giving support to patients who need it.

1. **Please answer each question carefully and tick the response that best describes your answer.**
2. **Please answer each question as honestly as possible.**
3. **If you are not completely sure which answer is most accurate, tick the box which you feel is most appropriate.**
4. **Please tick the 'no difficulty' box if a question does not apply to you.**
5. **Please do not spend too long on each statement.**

During the PAST MONTH:

	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty in maintaining your independence?				
Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)				
Have you had any difficulty managing your own personal care? (e.g. bathing, washing, dressing)				
Have you had any difficulty with looking after those who depend on you? (e.g. children, dependent adults, pets)				
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?				
Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability				

living allowance)				
Have you had any financial difficulties?				
Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)				
Have you had any difficulty concerning your work? (or education if you are a student)				
Have you had any difficulty planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)				
Have you had any difficultly with communicating with those closest to you? (e.g. partner, children, parents)				
Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)				
Have you had any difficulty concerning sexual matters?				
Have you had any difficultly concerning plans to have a family?				
Have you had any difficultly concerning your body image?				
Have you felt isolated?				
Have you had any difficulty getting around? (e.g. transport, car parking, your mobility)				
Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)				
Have you had any difficulty with carrying out your recreational activities (e.g. hobbies, pastimes, social pursuits)				
Have you had any difficulty with your plans to travel or take a holiday?				

Have you had any difficulty with any other area of your everyday life?				

Appendix 20: Study Advertisement

Would you be willing to take part in a research study?

We are a research team based at the University of Chester and are looking for people to take part in a research study on the wellbeing of people living with haematological cancer. The study is part of a PhD project that is investigating the unmet needs of people who have had a diagnosis of haematological cancer and how living with cancer affects a person's wellbeing and their everyday life.

Taking part in the study will involve completing a questionnaire about your needs, concerns and wellbeing.

If you are:

a) over the age of 16 and;

b) received a diagnosis of lymphoma, leukaemia or myeloma 18 months or more ago, then we would love to hear from you!

For more information or to receive the questionnaire by post you can contact the research team via the contact details below. You can also complete the questionnaire online by going to the web address listed below.

Brooke Swash
University of Chester
Department of Psychology
Chritchley Building
Parkgate Road,
Chester CH1 4BJ

Phone: 07827 807466

Email: b.swash@chester.ac.uk

Web address: http://formicweb.chester.ac.uk/webforms/?TAG=Longtermpsychologicaladjustment

Appendix 21: Questionnaire

The AAQ-II is presented below. The SCNS SF34, HADS and EORTC QLQ-C30 can be found under Appendix 19.

AAQ-2

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1.	Its OK if I remember something unpleasant.	1	2	3	4	5	6	7
2.	My painful experiences and memories make it difficult for me to live a life that I would value.	1	2	3	4	5	6	7
3.	I'm afraid of my feelings.	1	2	3	4	5	6	7
4.	I worry about not being able to control my worries and feelings.	1	2	3	4	5	6	7
5.	My painful memories prevent me from having a fulfilling life.	1	2	3	4	5	6	7
6.	I am in control of my life.	1	2	3	4	5	6	7
7.	Emotions cause problems in my life.	1	2	3	4	5	6	7
8.	It seems like most people are handling their lives better than I am.	1	2	3	4	5	6	7
9.	Worries get in the way of my success.	1	2	3	4	5	6	7
10.	My thoughts and feelings do not get in the way of how I want to live my life.	1	2	3	4	5	6	7

Appendix 22: Debrief Sheet

Dear ……,

On behalf on the research team, I am writing to thank you for taking the time to participate in our research study. You contributions are greatly valued. You are not required to do anything further or to provide any further information.

If you would like to receive a general summary of the results then please do let us know and we will be happy to provide this for you. At present, the data generated by the questionnaires is being analysed and we are confident that the information that you and your fellow participants were able to share with us will greatly contribute towards our understanding of the psychological health and wellbeing of people living with a diagnosis of cancer. I would also like to assure you that all of the information that you gave us will be treated confidentially.

Please feel free to contact us if you have any further questions about the study. Any questions or concerns that you may have relating to your medical condition or treatment would be best addressed to your GP or the cancer team at the hospital where you were treated.

Cancer can cause a great deal of distress and confusion no matter how long ago a diagnosis was given. If you think that talking to someone about your experiences may be of benefit to you, the following telephone numbers might be helpful:

Macmillan Cancer Support: 0808 808 0000

Cancer Help UK: 0808 800 4040

The Samaritans: 08457 909090

Once again, I would like to thank you for taking part in our research. We wish you all the very best in the future.

Appendix 23: Patient Information Sheet

Long-term Psychological Adjustment in Haematological Cancer Patients.

You are being invited to take part in a research study. Before deciding whether or not you would like to take part, it is important that you understand the purpose of the study and what taking part would involve. Please take some time to read through the following information.

What is the purpose of this study?

Living with a diagnosis of cancer can sometimes be difficult and can mean that people find themselves adjusting to a new way of living. Many people will find ways of managing and of coping with their illness, however, for some people it will have a negative impact upon their life and their sense of wellbeing. This study aims to assess how people adjust to living with, and beyond, a diagnosis of cancer and we are trying to better understand the factors that cause distress. Having a greater understanding of how people adjust to their diagnosis and the factors that play a role in this would mean that in the future we will be better able to prevent people from experiencing distress by providing more efficient support to those who need it most.

Am I eligible to take part in the study?

In order to take part in the study, you will need to match several eligibility criteria:

- Be over the age of 18
- Have, or have had in the past, a diagnosis of a haematological cancer (this can include any leukaemia, lymphoma or myeloma)
- Have received your diagnosis at least 18 months ago.

What will taking part involve?

If you do decide to take part, then you will be invited to complete a questionnaire that will contain questions about your life, how you are feeling and general questions about your wellbeing. There are two options for completing the questionnaire. You can

either complete the questionnaire online by going to the web page http://formicweb.chester.ac.uk/webforms/?TAG=Longtermpsychologicaladjustment or by contacting the research team via the contact details provided at the end of this information sheet and a questionnaire will be sent to you via post.

What should I do if I want to take part?

If you would like to take part in our study, please either go the web page http://formicweb.chester.ac.uk/webforms/?TAG=Longtermpsychologicaladjustment or contact the research team via the contact details provided.

If you any specific requirements, for example if you would like to receive the questionnaire in large print, then please contact Brooke Swash for an informal discussion.

Confidentiality

The data provided by you will only be used for the purposes of this study. Information will be stored securely and confidentially and in any reports, papers or write ups you will remain entirely anonymous. All data will be stored in accordance with the Data Protection Act and with University Research policies. All electronic data and analysis will be maintained on secure university computers. Once analysis is completed, data will be kept on a password protected CD in secure university archives. All paper documents will also be kept securely within the university. All archived research data will be confidentially destroyed after ten years.

What happens if I want further support after completing the questionnaire?

The questionnaire that you fill out will be used for research purposes only and all responses will be anonymous, as such the research team are not in a position to provide any further support or follow-up help in response to your responses.

Some of the questions on this questionnaire will ask about how you are currently feeling and how well you feel that you are coping. It is possible that thinking about these issues

could be upsetting or will raise some concerns for you. If you do feel that you would benefit from some additional support or would like someone to talk to about your diagnosis, we recommend that you either arrange an appointment to see your General Practitioner, or, for more general support you can contact the following organisations:

Samaritans: 08457 90 90 90

Macmillan Cancer Support: 0808 808 0000

Who can I speak to if I have any questions about my illness or the care that I receive?

This study is for research purposes only, as such the research team are not able to advise you on your illness. If you feel that you need to speak to someone about your condition, we advise that you contact your GP or the hospital where you received your treatment.

Who is organising and funding the study?

The research is being organised and carried out by a research team based at the University of Chester. The lead researcher is Brooke Swash although the team also includes Dr Nick Hulbert-Williams and Professor Ros Bramwell. The research is being funded by both the University of Chester and the Countess of Chester Hospital NHS Foundation Trust.

Who has reviewed this study?

Ethical approval has been sought from the University of Chester.

What if I am unhappy about any aspect of this study?

If you have any concerns or complaints regarding this study, please contact the Head of Department, Department of Psychology, University of Chester.

What will happen to the results of the study?

This study is part of a PhD project being completed at the University of Chester and will be written up as part of the thesis. In addition, the results will be written up as part of a

research paper that will be submitted for publication within relevant academic journals. In all cases, participants will remain anonymous.

If you would like to receive a summary of the results, please contact Brooke Swash. In addition, a summary of the research will be published in Lymphoma Matters.

Contact details for further information:

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